

PAEDIATRIC ONCOLOGY

ALMANAC 2023

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FOREWORD

Dear SIOP Members, Partners and Friends,

Over the past few decades, the field of Paediatric Oncology, across professions, has been transformed by unstinted efforts of many exceptional women. These women, despite innumerable obstacles, have broken through the proverbial 'glass ceilings' and achieved great success in advancing our understanding of childhood cancer.

This Almanac profiles many such women leaders and seeks to celebrate and honour their contributions. Each profile provides an overview of the woman leader's background, accomplishments and impact on their profession. Through these profiles, you will gain insights into the unique outlook and perspectives that women bring to the field of Paediatric Oncology.

It is our hope that this Almanac will act as a source of inspiration and motivation for current and aspiring women leaders in Paediatric Oncology, help to further promote inclusion, equity and diversity in the field and encourage more young women to pursue a career in Paediatric Oncology.

Thank you for reading the Almanac and please be sure to contact us with questions and suggestions: programs@siop-online.org.

Warm wishes.

SIOP Women Leaders in Paediatric Oncology Network

Chair: Faith Gibson (UK) **Steering Group Members:**

Sarah Cohen-Gogo (Canada/France) Monica Cypriano (Brazil) Amita Trehan (India) Adedayo Joseph (Nigeria) Eman Al-Shamsi (UAE) Giselle Saulnier-Sholler (USA)



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"If it was easy, anyone could do it."

SUSAN COHN USA

Professor Susan Cohn has devoted her career to caring for children with neuroblastoma and conducting clinical and translational research focused on understanding the biologic underpinnings of highrisk neuroblastoma to identify new therapeutic targets.

She has also led efforts to develop risk classification algorithms in the International Neuroblastoma Risk Group (INRG) Task Force and the Children's Oncology Group (COG). In collaboration with Drs. Samuel Volchenboum and Andrew Pearson, she has also created the INRG Data Commons, a platform that currently houses data on >24,000 neuroblastoma patients from around the world that are available to the research community.

She is conducting translational research with Dr. Mark Applebaum and Dr. Chuan He at the University of Chicago to investigate the epigenomic landscape of neuroblastoma and to develop liquid biopsy epigenomic biomarkers for response and survival.

In studies conducted with Drs. Monica Pomaville and He, she is investigating the biological implications of the m6A epitranscriptome and is testing the antineuroblastoma activity of inhibitors of METTL3, a writer that installs m6A RNA modifications.

Professor Cohn is also devoted to training the next generation of pediatric oncologists and has mentored numerous pediatric oncology fellows in both clinical and translational research.

Dr. Sharon Murphy greatly influenced my career. I first met Sharon when she was recruited to serve as the Hematology/Oncology Division Chief at Children's Memorial Hospital at Northwestern University. At the time, I was a young faculty member. Shortly after joining the Northwestern faculty, Sharon was elected Chair of the Pediatric Oncology Group (POG). Sharon introduced me the leaders of the POG Neuroblastoma Committee, including Dr. Robert Castleberry and Dr. Garrett Brodeur, both of whom also served as mentors for me. I learned very quickly the power of collaborative research and the importance of cooperative group clinical trials. I had the privilege of serving as the first Chair of the COG Neuroblastoma Disease Committee and have remained active in the COG since its inception in 2001. As an internationally recognized expert in lymphoma and a highly skilled female pediatric oncologist, Sharon also served as an important role model for me.

Dr. Andrew Pearson has also greatly influenced my career. I met Dr. Pearson, who is from the United Kingdom, in 2004 when we were asked to co-chair a new INRG Task Force by leaders of the Forbeck Research Foundation. The overall goal for the Task Force was to develop a consensus approach to pretreatment risk stratification. The INRG Classification System was was based on analyses of 13 variables in a cohort of 8,800 international patients. We quickly recognized the significant value of the data in this large cohort. A process to ensure these data are available to the research community was developed, and this enabled seminal studies, previously not possible with smaller patient cohorts. I have learned so much from Dr. Pearson's European approach to leadership, which differed a bit from my American approach. Specifically, he has taught me the importance of patience, developing consensus, civility, and working together.

On Challenges and Overcoming Them

I have encountered numerous challenges during my career. I found it very difficult to balance my life as a mother to young children and my career. I was fortunate to have a supportive husband who made sure dinner was ready every night for our children. This was not easy because my husband is also a physician with a busy practice. We also had a wonderful nanny who came to our home to help care for the kids when we were at work. However, I always felt that I was not doing all that I should as a mother, and I also felt I was not accomplishing all that I should at work. Figuring out how to "do it all" is not easy and remains a constant challenge. My family and my career are both very important to me. I eventually learned how to live with the realization that I needed to change my expectations about what can be achieved each day.

Pediatric oncology is a difficult career, and there are many challenges associated with this job. While caring for patients who do well is very rewarding, it is so difficult when a patient dies. As a young doctor, I remember not being able to control my emotions when one of my patients died. Although I have been working in this field for more than 35 years, I continue to be deeply affected by every one of my patients who dies. My motivation to conduct research focused on developing more effective treatments started when I was a pediatric resident caring for a precocious little girl with neuroblastoma, named Emily, who did not survive.

On Balancing Career and Other Life Responsibilities

I am fortunate to have a supportive husband and family. When my children were young, in addition to our nanny, we had extended family nearby who could provide help when needed. I first started my pediatric fellowship when my son was 3 months old. I met with my Division Head in advance of the fellowship and asked if my schedule could be modified when I started fellowship so that I could spend more time at home. I was able to begin my fellowship with an elective evaluating bone marrows rather than the hospital service. This provided an opportunity for me to transition into what eventually became a very busy fellowship year. I was fortunate to continue to have significant help at home during my career.

My Words of Wisdom for the Next Generation of Female Leaders

When I started medical school, I had no idea what type of career I would have. I knew I was going to be a doctor, and I realized quickly that I loved working with children. I would have told my younger self that if you are passionate about your work and pursue opportunities that arise, you will have a rewarding career. Although hard work is key, serendipity and luck also contributed to my success. I consider it a privilege to care for patients with cancer. New advances in pediatric cancer treatment are being made each year and survival rates continue to increase. However, more work is still needed. We must develop novel effective therapy for children with brain cancer and other metastatic solid tumors that are currently not curable. In addition, efforts to improve the quality of life of pediatric cancer survivors are critical. This will require a new paradigm for treatment strategies. We need to change our "more is better" approach and test less toxic, effective treatments that are individualized for each patient and their cancer. I am confident that those of you who are now embarking on this career will continue to make advances that will improve the outcome of children, adolescents and young adults with cancer.

SUSAN COHN USA



NISREEN AMAYIRI

JORDAN

Dr. Nisreen Amayiri is a paediatric neuro-oncologist at the King Hussein Cancer Center (KHCC) in Jordan.

She completed her Higher Specialization in Paediatrics at the Jordan University of Science and Technology and her fellowship in Paediatric Hematology Oncology at the KHCC. Following her graduation in 2011, she was appointed and continues to be in charge of the neuro-oncology service.

Dr. Amayiri is the recipient of the ASCO 2016 Life Award from the Conquer Cancer Foundation which enabled her to pursue her paediatric Neuro-Oncology fellowship at the Hospital for Sick Children (Sickkids)/Toronto in 2016/2017.

Recently in 2020 and through a My Child Matters grant, an initiative of the Sanofi Espoir Foundation, she is leading a national awareness project, HeadSmart Jordan, raising awareness about the signs and symptoms of brain tumors in children to allow timely diagnosis and referral.

Dr. Amayiri has several publications related to paediatric brain tumors. Her main clinical interest is to work nationally, regionally and internationally to improve the survival and importantly the quality of life of children diagnosed with CNS tumors in resource-limited countries.

She believes that this can be achieved through close collaborations and twinning with institutions and programmes in high income countries.

Having a great mentor early in my career had the biggest impact on my professional development. Dr. Eric Bouffet, the lead paediatric neurooncologist at Sickkids and former SIOP President, helped the KHCC to establish the Paediatric Neuro-Oncology service in 2003 through a strong and unique twinning programme between the two institutions. Through this collaboration, there was a significant improvement in the survival and quality of life of children with brain tumors in Jordan. He offered me invaluable guidance and support, helped raise my confidence and problem-solving abilities, and made it possible to establish an expanded international network of collaborations for clinical care and research.

The second influential relationship in my career was with ASCO. First, I received their International Development and Education Award (IDEA) in 2015, followed by the Long-term International Fellowship (LIFE) in 2016 which enabled me to get hands-on training in Paediatric Neuro-Oncology at Sickkids. This boosted my clinical skills and allowed me to experience clinical trials using innovative approaches, including targeted medications and immunotherapy. Upon my return to the KHCC, I worked tirelessly to make these medications available to my patients through compassionate access programmes. I am in the process of joining international prospective clinical trials for children with CNS tumors at the KHCC for the first time. Recently, in 2022, I joined ASCO Education Scholarship Programme aiming to build a better understanding of the cognitive sciences and adult learning theories to enable me to be more engaged in education and to advance my leadership skills. All these achievements would not have happened without the big support I received from my institution, KHCC.

On Challenges and Overcoming Them

The main challenges I faced at the start of my career were my limited knowledge in Paediatric Neuro-Oncology and lack of leadership skills' training. In the rapidly advancing field of Paediatric Neuro-Oncology, it was challenging for a recently graduated fellow to manage a large number of newly diagnosed (80-100 per year) patients with different tumor types.

In addition, being in charge of running difficult family discussions was very challenging. However, through the support of my colleagues at the KHCC and the wonderful twinning programme, patients received the best care possible. My colleagues at the KHCC and I were able to design safe treatment plans for our patients. Thanks to the twinning programme and our monthly videoteleconferences, we were able to design the most appropriate treatment plans, fine-tuned to our resources.

Through these discussions with our twinning programme partner, and the shared articles and guidance afterwards, we noticed an escalation in the team's knowledge over time. Twinning, if done in the proper way, is a great success formula to advance care in countries with limited resources. Subsequently, several regional countries joined our teleconferences where they are given the opportunity to discuss their patients' management plans and advance their knowledge.

To lead a team when you are the most junior was not easy. Your self-confidence and communication skills are tested every day. Nevertheless, three things helped me improve these skills: understanding myself better, improving my clinical knowledge, and having an experienced mentor who is ready to listen and provide advice. These challenges made me a better version of myself, more knowledgeable and wiser, and ready to take the lead and mentor younger colleagues.

On Balancing Career and Other Life Responsibilities

This has never been easy; working as a paediatric neuro-oncologist in a resource limited country is demanding, both physically and emotionally. Few things helped me find some work-life balance. My mother's support and encouragement kept me focused on the worth of my work and the important people in my personal life. Working on some research projects allowed me to distract from the stress of the clinical duties even if for a short time. Spiritual meditation helped me organize my life priorities and "re-charged" me whenever I felt overwhelmed.

My Words of Wisdom for the Next Generation of Female Leaders

Have a passion for your work; this is what will help you survive the tough times. Utilize every chance to expand your professional network; this is an invaluable resource for future opportunities. Find a mentor who is able to understand your values and career goals and who is enthusiastic and invested in your growth and support. And most of all, maintain a work-life balance!

NISREEN AMAYIRI JORDAN



"You are not here for the dress rehearsal."

TRACEY O'BRIEN

AUSTRALIA

Professor Tracey O'Brien is the Chief Cancer Officer of New South Wales, Australia and CEO of Cancer Institute NSW. An internationally respected clinician-researcher, Tracey is a paediatric oncologist and transplant physician with over 20 years of success propelling national and international excellence in research-led, patient-centred outcomes for children with cancer.

Tracey has co-authored over 120 research papers and several textbook chapters, leading to over 4,000 literature citations.

Tracey was the Director of the Kids Cancer Centre at Sydney Children's Hospital from 2016 to 2022, leading a team of 200+ clinical and research staff, and the Director of the Transplant and Cellular Therapy Program from 2004 to 2022.

Tracey is a strategic, collaborative, and inclusive leader and has held numerous high-profile leadership positions in cancer control, research and policy. These include Chair of the Cancer Australia Advisory, Vice-Advisory Chair (Asia, Africa, Australasia) for the Centre for International Bone Marrow Transplant Research, V/President; Australian and New Zealand Children's Oncology Group and board director Children's Cancer Research Institute.

In addition to her specialist medical training, Professor O'Brien has an MBA and Master of Law and dedicates significant time to training the next generation of clinician-researchers, mentoring over 35 paediatric oncology multidisciplinary clinicians and researchers.

Throughout my career, there has not been a day when I have not learned something new. Remaining curious and hungry for knowledge is critical to innovation. My paediatric and adolescent patients and their families have been the most significant source of influence, inspiring me to solve the problems that matter most to patients.

I believe that excellence in medicine comes from great teamwork. As a leader, I always strive to ensure that all members of our paediatric cancer multidisciplinary teams are empowered and working to the highest scope of their practice.

Other key influences have been executive leaders in policy and government. Their mentorship has been invaluable in maturing my understanding of making large-scale sustainable change at the population level, particularly informing my interest and focus on better serving vulnerable and underserved populations to close the equity gap and provide excellence in outcomes for all people with cancer across the state

On Challenges and Overcoming Them

I have certainly had times in my career when I have taken on more than I should have, leading to unnecessary stress on me and, likely, on others around me. I have actively worked on when to say NO, setting priority goals, mastering better delegation and not being a perfectionist – near enough is good enough.

On Balancing Career and Other Life Responsibilities

Working in paediatric cancer gives one an intimate and painful view of how fragile life can be and that, as a parent, the most important thing is the health and well-being of our children. In doing so, I hold this close and spend as much quality time with my kids as possible; being present in the moment is key. I treasure family holidays and always have one planned to look forward to, and I exercise and meditate – nearly every day.

Spending time with friends who don't work in healthcare is also something I consciously do and enjoy for that balance. The older I am and the more senior roles I have taken on, the more I appreciate the critical need for work/life balance to ensure that I perform at my best and how important it is for me as a leader to role model these behaviours for others.

My Words of Wisdom for the Next Generation of Female Leaders

Follow your passion. Reflect often – we are all leaders in evolution.

Lean in and grab opportunities with two hands as they arise.

Always operate just outside your comfort zone to maximize personal growth.

Don't do what you think you should do in terms of career progression if it doesn't feel like a natural fit; find what you are a natural at or can add value where others can't and learn from people in different sectors and industries.

Ask questions and, above all, be a great team player, build relationships and networks and be a great listener – having excellent soft skills will take your leadership journey further.

TRACEY O'BRIEN AUSTRALIA



ANA LYGIA PIRES MELARAGNO BRAZIL

Ana Lygia Pires Melaragno graduated in 1984, determined to work in Oncology. She started in adult patients' care, in postoperative oncologic surgeries: the care was complex and the knowledge was small. There were no courses and the learning was on the job.

She then joined the Foundation Antônio Prudente, one of the largest cancer hospitals in Brazil, where she worked for about ten years. She learned how to provide care and soon got involved in the implementation of educational processes there.

Training the staff and attracting the interest of professionals to oncology was urgent. She organized courses and activities to train and integrate professionals that were interested. She contributed to the creation of the first school to train mid-level professionals in this specialty. Education became a mission because only knowledge guarantees patient safety.

In 1997, in Campinas, Ana Lygia Pires Melaragno worked at the Boldrini Children's Center, specialized in Oncology and Haematology, and entered Paediatric Oncology. Since then, she has dedicated herself to the SOBOPE Nursing Committee, organized courses and scientific events, and promoted training throughout Brazil. She worked on the integration of teaching and assistance, presenting Paediatric Oncology to students, including Paediatric Oncology as a specialty for Brazilian nurses.

Many people influenced my career, helping me choose the field of Oncology and specifically, Paediatric Oncology. I watched a class on Oncology, still in undergraduate school, when a doctor was showing the head and neck surgeries and from that moment on I decided that I wanted to take care of those people and offer my best. The class, centered on the medical practice concerned with removing the tumour at any cost to the patient, showed me the importance of care and teamwork. This class also showed me that it was not enough for the renowned surgeon to master the content because to be an educator, one needs more than this, so I sought my training in pedagogy some years later.

Two people influenced me a lot. One was Nurse Odete Gazzi, Manager of Nursing at the Antônio Prudente Foundation, from whom I learned posture and respect for patients and their families, dedication to care even when cure was not possible. She motivated me to pursue teaching in this area because she identified in me the necessary competencies for this activity. The second person was my husband of 31 years, Dr. Renato Melaragno, who is a paediatric oncologist. Paediatric Oncology is about working as a team, sharing decisions, where the nurse plays a fundamental role due to our proximity with the family and the patient all the way through. Paediatric Oncology is a link between the teams who must be scientifically prepared and who should have the necessary skills for safe care for everyone-patient, family, and professionals. Nurses are the educators of the team of healthcare professionals, patients, and families because a lot of information and routine changes occur during treatment.

On Challenges and Overcoming Them

I believe that my biggest challenge was dealing with the lack of information and specific knowledge about cancer, its signs and symptoms, therapeutic modalities, and chances of cure, and understanding how this lack of knowledge impacts the survival curve. This lack of knowledge reinforced the myths of an incurable disease, associated with a view of a suffering death. This kept professionals away; there was difficulty in hiring because candidates were rare. I heard that I was a special nurse because I was working with these patients, but I wanted to be a specialist. Seeking knowledge and sharing was the strategy I used to attract and retain professionals. I developed specific training programmemes for newcomers and gave job opportunities to new graduates, which allowed me to build solid teams in the institutions where I worked. Accessing undergraduate students was another strategy to sensitize future professionals and awaken their interest in Paediatric Oncology. Developing permanent education programmes in assistance and teaching institutions were also great challenges that I faced for 30 years. Teaching about the therapeutic modalities, developing skills and approaching the nurse's protagonism is a huge challenge.

Another great challenge is the training of nurses specialized in Paediatric Oncology, the creation of courses coordinated and taught by professionals with expertise in the area, as well as the active participation of nurses in medical associations such as the Brazilian Society of Paediatric Oncology (SOBOPE) and the Brazilian Association of Nursing. I am also dedicated to talking about signs and symptoms for nurses so that they can contribute to the identification of suspicious cases through the nursing consultation. I believe that if there is more information about this we can improve the cure rates in Brazil.

On Balancing Career and Other Life Responsibilities

I think it is important to be aware that we are only one person with several important roles at the same time: the nurse, mother, wife, daughter, friend.....same person. Integrating all the roles is difficult and for this, we need the support of family and friends. But my husband was fundamental because he always encouraged me and took care of our son so that I could be at work, caring for my patients and their families.

So, family was fundamental, and besides this, working in institutions that recognized their role and responsibility in professional education and training allowed me to conduct training sessions in other states and institutions. There were many invitations. I could contribute to different realities, considering that Brazil is a big country and the needs are immense. I was able to get to know most of the Brazilian institutions, and this added knowledge that I applied to my work and to external training courses I led. The seriousness with which Brazil takes care of its children, offering quality treatment to all through the Unified Health System, makes our professional commitment worthwhile. To the Unified Health System, we are equal.

My Words of Wisdom for the Next Generation of Female Leaders

The advice I would give to a 25-year-old would be to manage your career, be a nurse with focus, choose the area you are going to dedicate yourself to, acquire specialized knowledge, and make a difference.

Nurses can be involved in management, assistance, teaching, and research, but it is important to have this awareness and focus on something that we want to improve or contribute. I see professionals with many different specialization courses but with no depth in any of them. We have to manage our career in a way that we can be proud of our profession, feel a sense of accomplishment and professional satisfaction. We must get involved with our professional associations and work for better nursing. Working in Paediatric Oncology requires professionals who take charge of their careers and are committed to the patients and their families.

ANA MELARAGNO BRAZIL



JEANNETTE PARKES SOUTH AFRICA

Jeannette Parkes is the Head of Radiation Oncology and Radiation Medicine at Groote Schuur Hospital at the University of Cape Town in South Africa.

Her clinical portfolio includes management of CNS tumours, bone and soft tissue tumours and paediatric radiotherapy. She is President of the College of Radiation Oncology of South Africa and clinical director of the Access to Care (Cape Town) programme.

Internationally, she is the low- and middle-income country (LMIC) representative on the Executive Committee of the Paediatric Radiation Oncology Society (PROS) and has been a team leader of SIOP Global Health Network's PROS LMIC Working Group since 2016. She is the radiotherapy representative on SIOP Africa's executive committee, as well as SNOSSA (Society of Neuro-Oncology in Sub-Saharan Africa) executive committee.

She has contributed to the WHO Working Groups for the technical package associated with the Global Initiative for Childhood Cancer (GICC) and has contributed to several international adapted treatment guidelines for treatment of paediatric cancer in low and middle income countries.

She is editor of the soon to be released IAEA guideline for paediatric radiation oncology, and has acted as PROS/ARIA coordinator and now chairperson of the ARIA AMG(adapted management guideline) steering committee.

"It always seems
impossible
until it's done."
Nelson Mandela

My dad is a medical specialist. His work, work ethic, wisdom and care for his patients and staff was an example to me as a teenager. I wanted to be part of the care community like he was, and this made me decide to apply to study Medicine.

From the time I joined the Radiation Oncology programme, I was drawn to paediatrics. Dr. Jenny Wilson was my immediate supervisor. Jenny had every patient's notes in her head, could plan, scan and treat patients herself. Her technical knowledge and knowledge of brain tumours was unrivalled. I wanted to be just like her. At that time, we were able to treat our paediatric patients with protons, and Jenny was my mentor and my teacher. Jenny died unexpectedly at the age of 50, and I vowed to continue her legacy.

In later years, my greatest strengths have lain in collaborations with colleagues. In the advocacy space for children with cancer, I have been profoundly influenced by Alan Davidson and Simon Bailey who continue to support and collaborate on projects to improve cancer care for children in LMIC. But the idea of including advocacy and LMIC as a separate stream in PROS, came from Natia Esiashvili. Natia has guided PROS LMIC and then PROS with her care and compassion and has influenced how I think about advocacy and possibilities to improve radiotherapy care for children globally.

All of these people have somehow influenced my thinking, my career choices and development and my goals, and I thank them.

On Challenges and Overcoming Them

At the time I started doing paediatric radiotherapy, I really struggled with the emotional side of the job. Counseling distraught parents, children who relapsed and children who had to live with the late effects of their disease and treatment was difficult. I think coping comes with experience and the knowledge that we can all only do our best. But it is made easier by always keeping up to date with the latest information, and making sure that what I suggested was the best possible treatment in our resource constrained environment. I surrounded myself with colleagues who knew more than I did that so I could learn from them. The PROS Society is unbelievably generous and my colleagues there are always available to help.

The other challenge that I identified early on is the inability of many countries in Africa to provide the services needed to treat children with cancer. The issues relate to teaching and training, equipment and infrastructure provision and drug availability to name a few. I have made it my business to actively campaign for improved radiotherapy services throughout Africa and other LMIC and for paediatric radiotherapy services in particular.

I think that the multi-disciplinary collaboration between international global organisations and professional groups within paediatric oncology is quite astounding. I am constantly reminded of what a privilege it is to work with such people. The group effort towards helping children with cancer in LMIC can never succeed without a multitude of individuals and organisations who all work to this end. But on a personal level, it is the individual international relationships that I value and that have made me stronger.

On Balancing Career and Other Life Responsibilities

I have been extra-ordinarily lucky in that my family has supported my career choices and my work whole-heartedly. My parents have looked after our children when they were little, done homework and driven them around. My husband has taken on more than his fair share of the admin around the house, and although I may not have been as omnipresent as some other mothers, I have always tried to be there for important occasions, and to be present mindfully so that I can enjoy the occasion.

I also have a wonderful group of doctors whom I work with at my hospital. They are extremely supportive, often taking on additional responsibility in times of need, helping us all to balance family responsibility when the need arises.

More recently, I have learned to better make some time for myself and to recognize the need for time away from work and projects to facilitate health and ongoing inspiration. This facilitates better projects and a better me in all avenues of my life. This was brought to stark relief for me when I was diagnosed with breast cancer in 2018, and suddenly became a patient, undergoing surgery, chemotherapy and radiotherapy—all the things I usually counseled other people about. It was difficult, but a wake-up call that I have to be kinder to myself, sometimes rely on others, and find that balance.

My Words of Wisdom for the Next Generation of Female Leaders

If I could give advice to myself at age 25, I would say "Choose a career path in something that excites and motivates you. Don't waste time doing work that doesn't."

To the younger generation of paediatric oncologists, I would suggest to choose their collaborators carefully. Always surround yourself with colleagues whose opinion you respect, and who have the same values as you do. Take your job seriously, and don't underestimate the toll that overwork places on your health and your family. You must work hard to achieve that work-life balance. Have fun! Make sure that your work offers the opportunity to mix with people you like, and do projects that are worthwhile and fulfilling.

JEANNETTE PARKES

SOUTH AFRICA



"I am the river that is often quiet and still, offers nourishment to those who choose to visit, seeps into gaps unnoticed, can be difficult to contain and is sometimes a powerful force"

JEANETTE HAWKINS UK

Jeanette Hawkins is the Chief Nurse at the <u>Children's</u> <u>Cancer and Leukaemia Group</u>, funded by <u>Young Lives</u> <u>vs Cancer</u>.

As the Chief Nurse, she works across both organisations providing insight, advocacy and leadership in children's cancer nursing.

Jeanette trained in the Queen Alexandra's Royal Army Nursing Corp and later joined the NHS. She worked at Birmingham Children's Hospital (BCH) in Children's Cancer services for 25 years, with 12 of these years as Lead Cancer Nurse, where she completed an Masters in Science (MSC) in Advanced Nursing Practice.

Jeanette pioneered a number of service developments at BCH, including nurse prescribing, advanced practice, and family-centred models of care. Other achievements include the NICE Neutropenic Sepsis Guideline Group, Deputy Chair of West Midlands Children's Cancer Network Coordinating Group and two terms on the RCN Paediatric Oncology Nursing Forum Steering Group. She supported the adaptation of the adult cancer Telephone Triage Toolkit to a paediatric version with a published article on this project. Jeanette has other publications relating to CYP cancer.

More recently, Jeanette project managed the review of the 'Career and Education Framework for CYP cancer nursing' 3rd edition. In 2018, Jeanette visited Myanmar with World Child Cancer to support developments in specialist play. Jeanette joined Super Shoes as a Trustee and volunteer painter in October 2022.

I think all of us are helpfully influenced by so many people across the span of our lives. Sometimes, the smallest of interactions with a person makes a lasting impact on you. It's easy to look towards more experienced, more senior, more well-known or prominent influential people, and of course, I have been positively guided by many of them. Some of these beacons of light spotted my talents and skills (even when I couldn't see them), encouraged me, pushed me, and guided me (often when they weren't aware of it). I'm cautiously naming people as I'm sure to miss some: Mrs. Spencer (my English teacher at school), Sue Woodhouse (Ward Sister at BCH), Moira Bradwell (Day Care Manager at BCH), Rachel Hollis (RCN and SIOP colleague), Dara de Burca (Social Work Director), Faith Gibson (Researcher), Julia Chisholm and Pam Kearns (Consultant Oncologists), Ashley Ball-Gamble (CEO). They stand out because they exibited 'generosity of leadership,' meaning they gave their time, trust, and knowledge freely that helped facilitate development opportunities.

In some ways, though, the most important influencers were my peers, juniors, children with cancer and their families. These were the wonderful people who taught me the job. The role models, the educators, the ones who gave critical challenge, often kindly and sometimes harshly. Subtle nods of approval, nurturing words, or a flash of disapproval would usually steer me to a new understanding of a situation. I couldn't possibly pick out names here (far too many to mention) but dear colleagues past and present, children, young people and families, you know who you are (and if you doubt I mean you, if we worked together or interacted professionally you will be on my list). I owe such a debt of gratitude to everyone.

On Challenges and Overcoming Them

In 2000, when our children were aged 2 and 4 years, I was diagnosed with cancer. As a child, my mother had left home when we were young and I'd vowed that if I ever had children, I would never leave them, and then cancer came and threatened to do just that. It came close on the back of previous periods of maternity leave and returning to work after treatment was harder than I allowed myself to recognize at the time. I felt disconnected from the team and there were patients I knew nothing about but whom my colleagues knew well. I continued my MSC during treatment. When I returned, I was trying to establish a completely new role in the service. I don't think we were as good then at recognizing or supporting mental health in the workplace, so I just pushed on and worked through it. I'm much more aware these days of checking what other pressures colleagues have in their lives.

The second biggest challenge came because of COVID. I was working for Young Lives vs. Cancer and had an exquisitely

experienced team of nurse educators who were going out into local hospitals to educate and teach clinical skills so that families could access more care closer to home. We had the report on a two-year, externally-assessed service evaluation which showed excellent results. COVID lockdowns meant that charity income dropped significantly, and we had to streamline services. I had to make my team redundant, and it was a soul-destroying thing to do. I usually trust resilience to get me through things but for the first time, I reached out and had some coaching during this time. This was immensely valuable and allowed me share confidentially my thoughts and feelings. I would absolutely recommend coaching for anyone going through a difficult situation at work to help get perspective and self-care.

On Balancing Career and Other Life Responsibilities

Without doubt my husband and children have been the biggest support in enabling my career. My husband carries the lion's share of household chores assisting my work focus. I can easily be a workaholic so it's important for me to balance that. We have two Airedale dogs who make sure I get out for a long walk every day. We love being in the countryside and camping holidays with the dogs in beautiful parts of Britain. To keep myself active, I have also practiced Tai Chi and Qi Gong for the last 15 years. I love the combination of mental challenge, learning the forms and martial arts interpretation, the physical benefits of wholebody movement and the meditative elements where you become completely absorbed in something other than daily pressures.

I enjoy water-colour painting. I've had to adapt to acrylic painting more recently since I joined SuperShoes and am learning to paint on canvas. I've completed my first pair of shoes for a child with cancer and hope to do much more of this when I retire and have more time. It's been interesting too, researching characters to paint that the children request.

My Words of Wisdom for the Next Generation of Female Leaders

I am an extreme introvert. Leadership isn't something I sought out at 25, although it seemed to keep finding me! Later in life, I learned about the personality profile of 'confident introverts.' The advice I would have given my younger self is to embrace who you are and learn how to use it. Learn what exhausts you and what nourishes you in order to help you stay in balance. I also often found myself thinking differently from others. I used to think it was me that didn't quite understand the world the way others seemed to. My older self now knows that sometimes, I was just seeing it ahead of others due to foresight and horizon scanning. So now I'd say: "don't be afraid of showing your passions and stick to what you believe in."



"Passion never fails Just do it."

PURNA KURKURE INDIA

Dr. Purna Kurkure is currently a Senior Advisor, Clinical Collegium for Oncology Services Narayana Health (NH) Group, Head of the Department of Pediatric Haemato-Oncology & Bone Marrow Transplant at NH-SRCC Children's Hospital at Mumbai.

She has carved a niche for herself in the field of oncology after 33 years of services at Tata Memorial Hospital, Mumbai and retired as Head of Department of Pediatric Oncology in 2015. She has contributed a great deal towards the development of pediatric oncology in the sphere of service, education, and research in India and in the Asian subcontinent, winning many accolades.

She was President of the SIOP Asia Continental Branch (2007-2010) and was the President of a successful 2007 SIOP Congress in Mumbai. She was Consultant to the subcommittee on SIOP Pediatric Oncology in Developing Countries (currently the SIOP Global Health Network). She is a member of Steering Committee of the Asian Paediatric Haematology Oncology Group (APHOG) since 2012 where she currently serves as the Executive Council Member and Treasurer. She is a Founding Member and Co-convenor of Pediatric Hematology Oncology (PHO) Chapter of Indian Academy of Pediatrics (IAP). She served as Treasurer, Secretary and President of the PHO Chapter (1987-1999) and contributed towards strong foundation. She also served the Central IAP as Executive Board Member (1999-2000) and Treasurer (2020-2021).

Currently, Purna is the President of the Indian Society of Neuro Oncology, Joint Secretary of the Central IAP, and a Joint Managing Trustee and in charge of the Survivorship and Rehabilitation Division of the Indian Cancer Society (ICS).

I started my career in the combined department of Medical and Paediatric Oncology in 1982 at Tata Memorial Hospital (TMH). As a trained paediatrician, I was convinced at outset that a "child is not a miniature adult." Childhood cancers are different from adult cancers and need to be treated differently.

The hallmark of success in paediatric oncology is the multidisciplinary approach executed through carefully orchestrated combined modality team comprising of a paediatric oncologist, a paediatric surgeon, a radiation oncologist, and various diagnostic specialists. I was exposed to the multidisciplinary tumour board concept during my training at the Royal Marsden Hospital, London, in 1981 under tutelage of Dr. McElwain TJ and learnt haematopoietic stem cell transplant under Dr. Ray Powles. I was fortunate to get a visiting fellowship award by Imperial Cancer Research Funds, London, to receive training in Paediatric Oncology under Prof. J. S. Malpas at St. Bartholomew's Hospital, London, and training in immunophenotyping in leukemia from the pioneer in the field, Sir Melvyn Greaves.

This comprehensive training helped me in developing Paediatric Oncology Programme at TMH. I was a team member for first Bone Marrow Transplant in India in 1983. I contributed towards development of academic programmes in TMH and in India. I was involved in developing curriculum in Paediatric Oncology for its recognition as paediatric subspeciality by Medical Council of India. I am a mentor and examiner for the board exam in Paediatric Haematology and Oncology.

Childhood cancer survivorship is a recent focus for research because of the high curability of childhood cancers. My postgraduate teacher, Dr. Meena Desai, founder of Pediatric Endocrinology in India, inspired me to explore endocrine late effects of cancer therapy in childhood cancer survivors. I got an opportunity to be a Visiting Physician at St. Jude Children's Research Hospital, USA, in 1990. Drawing inspiration from the After Completion of Treatment (ACT) Clinic at St. Jude Children's Research Hospital and under the mentorship of Dr. Melissa Hudson, I could start an organized survivorship care in India, by starting ACT Clinic at TMH in February 1991 and promoting a Childhood Cancer Survivors' Support Group-UGAM in June 2009 under umbrella of ICS. I initiated a survivorship module PICASSO (Partnership In CAncer SurvivorShip Optimization) in 2017 under the Cancer Survivorship and Rehabilitation Division of ICS. PICASSO is holistic survivorship and rehabilitation module being implemented in partnership with Pediatric Cancer Units (PCU). The objective is to facilitate the PCU to start hospital-based ACT Clinic where medical assessments are done by pediatric oncologist and psychosocial care is taken care of by ICS for holistic care of survivors.

On Challenges and Overcoming Them

Cancer survivorship has been my passion since the early part of my career. TMH is a busy tertiary cancer center drawing patients from across India and neighboring countries. The priority in the 1990s was to get better organized for delivering curative treatment, better supportive care, improve survival, decrease abandonment of treatment, and bring majority of childhood cancer patients in the network for treatment.

As an active member of SIOP PODC, I along with my colleagues from major centers launched National Training Program in Practical Paediatric Oncology in 1998 under umbrella of PHO Chapter of IAP and supported by SIOP to increase awareness among paediatricians about early diagnosis and prompt referral for curative goal. Treatment abandonment due to logistics of prolonged stay in metropolitan cities and due to lack of finances for treatment were addressed by starting Home Away from Home in Mumbai in 2006 and subsequently in major cities in partnership with busy PCU in collaboration with St. Jude Child Care Center. Financial difficulties were addressed through unique financial model of Cancer Cure Fund of Indian Cancer Society. Survivorship issues were not considered a priority with these overwhelming challenges. Cancer survivorship seemed very abstract. I had huge responsibility of fulfilling my duties as pediatric oncologist. I was convinced that this will be a need of the future and we must make a beginning. I did not get much support initially in the form of dedicated clinic space and protected time to conduct ACT clinic. But I pursued the matter and subsequently, it got organized as a well-established entity at TMH. I have great satisfaction of leaving behind a legacy at time of my retirement which is still going forward and contributing to this field immensely.

On Balancing Career and Other Life Responsibilities

I practiced strict compartmentalization of my workplace and home, never carried forward problems of one compartment to other and tried to give my best at both fronts. My husband, Dr. Arun Kurkure, a surgical oncologist who succumbed to colon cancer in 2012, was my great support and inspiration. He was a Managing Trustee and Hon Secretary of ICS. He was also on the Board of Directors of UICC and was well conversant with holistic approach in cancer care and significance of therapeutic alliances. He was my friend, philosopher and guide who facilitated the execution of my projects and helped in nurturing my dreams. I can never forget the support of my daughter, Dr. Durva Kurkure, now a Radiation Oncologist, who sacrificed small pleasures of childhood in pursuit of my dreams. Unconditional love and support of my parents and extended family have been the greatest strength for me. Almighty is

PURNA KURKURE INDIA

kind to bless and give me opportunities and physical and mental abilities to continue my work postretirement, with passion.

My Words of Wisdom for the Next Generation of Female Leaders

My advice to the younger generation now embarking on a career in pediatric oncology will be to pursue a career with passion and not as an instrument for worldly survival. Keep future developments in your focus and identify a niche area which you would like to pursue for the betterment of your patients. Children with cancer are at center stage of all our activities and guide us. Always listen to them and to your heart. We advocate and practice Evidence based Medicine but also respect Experience based Medicine.

PURNA KURKURE INDIA



MARTHA GROOTENHUIS

NETHERLANDS

Prof. Martha Grootenhuis graduated as a health psychologist in 1989 and subsequently undertook a PhD examining psychological coping in paediatric oncology.

This was the beginning of a long career in pediatric psycho-oncology. She now leads the Psycho-Oncology Department at the Princess Maxima Centre for Pediatric Oncology (the Netherlands) and she leads a large research programme as an academic professor.

Embedded in her department is the KLIK PROM Portal, which provides monitoring and screening in clinical practice, and the PROM Core facility, which facilitates the use and support of patient-reported-outcomes measures in clinical care and research.

Over the years, she has specialized studying the psychosocial consequences for children and families with chronic diseases and childhood cancer. She has supervised many PhD-students and published almost 300 papers. She has been an Associate Editor for several journals including Supportive Care and Cancer and European Journal of Cancer, and now EJC-Pediatric Oncology.

She is proud of being the Founder and Chair of the SIOP Pediatric Psycho-Oncology (PPO) Network (2007-2022), establishing a solid position for psychooncology.

In 2014, she received an award by the National Association of Medical Psychology for outstanding achievements in paediatric psychology.

"The most beautiful things in life are free and priceless."

My first supervisor, Dr. Bob F. Last, was very influential in my early career. He had been a clinical psychologist in a paediatric hospital for many years. He studied open communication about childhood cancer diagnosis in the 1980s, which at that time was very new and innovative. The reflection about double protection between family members was the basis for my PhD trajectory. We worked out a theoretical model on secondary control strategies which is still applicable today. His clinical reflections supported me to grow into a researcher with a strong clinical foundation, which aided me ever since.

From the Paediatric Psychology literature, the Integrative Trajectory Model of Pediatric Medical Traumatic Stress, in which Dr. Anne Kazak (United States) was involved became very important. Her focus on medical traumatic stress, as well as the Psychosocial Preventative Health Model (which stresses that the diagnosis and treatment of paediatric illness including paediatric cancer affects and is affected by multiple levels of the social ecology, including patient and caregiver physical and psychosocial health) guided me in my clinically-focused research programme. The Psychological Assessment Tool (PAT), developed by Professor Kazak, has guided us in the monitoring and screening we undertake with families. These models are the basis of the psychosocial care we provide in our Centre, and what we teach to all our professionals.

In 2008, the PPO Network, including Dr. Maria McCarthy from Australia, invited Dr. Kazak as a speaker in Berlin. Thereafter I dared to invite myself to Dr. McCarthy's and Kazak's hospitals to explore our mutual research ambitions and learn from their experiences. Both these visits kicked off friendships which still continue. They both have provided me with mentorship, bicycles trips all over the world and most of all fun and a "family feeling" during the SIOP meetings.

On Challenges and Overcoming Them

I now have worked for 30 years as a psychologist in the medical setting. Functioning as a psychologist in a medical setting is not self-evident and does not yet receive the recognition and appreciation it deserves. Challenges have included being a woman and psychologist in a male dominant medical setting. I have learned through the years that in our society, values are attributed to almost everything and certain attributes can be very dominant in a hospital setting. These attributes and unconscious biases refer to pre-clinical research or social science, to questionnaires or microscopes, to men and women; there are values about doctors and about psychologists, about surgery or counselling, teaching or publishing, but also on survival and quality of life. These values influence perceptions, communication, choices, positions, prioritization, valuation, money flow, salary, and even referencing articles. Learning to see these patterns has

helped me understand the barriers and facilitators to better positioning myself in the medical setting. I have also learned to recognize that not everything is arrogance but often ignorance.

On Balancing Career and Other Life Responsibilities

Credits go to my partner Paul for standing next to me and sometimes behind me! I truly believe men who have female partners who are a professor are "different". My husband never had a problem with the fact that I had a full-time job or with me being the main breadwinner. We worked together in the care of our children and accepted each other's strengths and weaknesses. We accepted that sometimes only being there was good enough. So not the nicest treats at school, not a tidy and clean house. I hardly ever iron. Weekends and family holidays were essential and still contribute to the foundation of our family's well-being. As well as going to concerts, sharing music and dancing in the kitchen.

My Words of Wisdom for the Next Generation of Female Leaders

If I could give advice to myself at age 25, I would tell myself: be gentle with yourself! Be happy and proud of what you do, and don't depend on the outside world to give you credit for it. Sometimes good is good enough and it doesn't always have to be more. More is not always better. Nowadays, I see many young people who set the bar high, want to participate in everything and want everything to be fun as well. No one does only fun work, but it is undeniable that you can only persevere with hard work if it gives you enough satisfaction. Therefore, I would advise young professionals to seek the company of colleagues in the world- try to find opportunities to visit them and explore collaboration. I wish I would have had this experience earlier in my life. The paediatric psycho/oncology world is small so we can all benefit from a network.

We all know from working with families with a child with cancer how precious life is, and how important it is to celebrate this with our loved ones. I learned from my sister whom I lost to cancer and whom I miss: The most beautiful things in life are free and priceless. I try to live accordingly.



"If a job is worth doing, it is worth doing well."

MICHELLE HABER AUSTRALIA

Prof. Michelle Haber is Executive Director of Children's Cancer Institute, the largest children's cancer research facility in the southern hemisphere.

With colleagues Norris and Marshall, she developed PCR-based technology for detecting minimal residual disease in children with ALL, which led to a doubling of survival rates in children with high-risk disease. She worked with colleagues Norris and Ziegler, as well as Hogarty (Children's Hospital of Philadelphia), to translate her studies on polyamine inhibition into international neuroblastoma clinical trials.

Her studies on the chromatin modifier, FACT, and its inhibition by CBL0137, conducted with Norris, Ziegler, Marshall, as well as Gudkov (Roswell Park Cancer Institute), have also led to an international COG trial.

She established and has led the ZERO Childhood Cancer national precision medicine programme, which has enabled all Australian newly diagnosed and relapsed high-risk child cancer patients to have tailored therapy targeting the specific genetic and biological characteristics of their individual tumour and which, by end 2023, will be available to every Australian child with cancer.

She was appointed a Member of the Order of Australia (2007), an Inaugural Fellow of the Australian Academy of Health and Medical Sciences (2015) and a Fellow of the Australian Academy of Science (2022).

Dr. Susan Horwitz, Fellow of the US National Academy of Sciences and former President of the American Association for Cancer Research (AACR), has been a significant influence on my career. I first met Susan when I was a graduate student at my first local conference in 1982, where Susan was one of the international invited speakers. There were few women graduate students at the meeting, and Susan made a point of speaking with us all after dinner, which made a deep impression on me at the time. At my first international meeting, several years later, I met Susan again where she remembered me warmly and urged me to keep in contact. When I knew my husband would be doing postdoctoral studies in New York, I contacted Susan to see if I could work in her lab at the Albert Einstein College of Medicine (New York), and she supported me in attracting a UICC Training Fellowship to work with her. From my relatively short time in Susan's laboratory, I was able to publish an influential paper on identification of tubulin isotypes, an area of research subsequently expanded by my own graduate student, Maria Kavallaris, who undertook her post-doctoral studies with Susan. During our time in New York, Susan welcomed our family not only into her home but also to visit her holiday house in the Berkshires. Susan's style as a research leader and her close relationship with her husband, Marshall, also a Professor at Albert Einstein, greatly influenced my husband and me, and we aspired one day to be two Professors, as successful and happy as Susan and Marshall (which we have been fortunate to achieve). Susan and I have kept in frequent touch over the years and she has been a constant supporter and advocate for me, serving as a referee for most of my awards.

On Challenges and Overcoming Them

I experienced a significant challenge early in my career when my husband, then a Physician trainee, needed to undertake overseas post-doctoral studies in order to secure a teaching hospital appointment on his return. I had just established my own laboratory in Sydney, Australia, with new grants and graduate students, and it was not feasible for me to leave my group for 2 years. However, I was committed to supporting my husband's career and neither of us wanted to be separated for any length of time, so we needed to find a compromise plan. That was when I applied to Susan Horwitz's lab for a 3 month Fellowship, during which we enrolled our children, aged 5 and 7, in a New York school. For the remaining 2 years of Paul's postdoctoral studies, I travelled backwards and forwards 6 times between Australia and New York with our children, so I could continue supervising my lab group in Sydney whilst spending time as a family in New York, and continuing my work in Susan's lab. We managed not to be apart for more than 6 weeks at any time, by staying in New York across all the Australian school holidays, and bringing with us a different friend or relative each time who took the children on outings while I worked, in return for a free stay in New York. We turned a

challenging situation into an adventure, meeting each time we flew into the USA in a different city for a long weekend as our allowed stopover, which was always exciting. We went into debt for our travels but never regretted it. This taught me that challenges can be overcome with sufficient creativity and determination, and this strengthened our marriage and our relationship with our children through what was quite a remarkable time.

On Balancing Career and Other Life Responsibilities

My life has been a constant juggle of career and family, both of which have been extremely important to me. My husband is a clinician scientist, with a busy career as a Head of Department in Sydney's leading teaching hospital, as well as leading a substantial research group in addiction medicine, and so we have constantly had to juggle our commitments and share the care of our children. He was always willing to look after our children when I travelled interstate or overseas for work, and to feed and put them to bed if I was working late. I arranged for university students to collect our 2 older children from school and take them to their grandparents, after-school activities or after-school care, from where I would pick them up. When I was 41 and already Acting Director of our Institute, we decided to have a third child, and from there, we needed a nanny to help support the logistics of our growing family. I tried my best to attend as many school functions and special occasions for our children as possible, but I know we missed a number of them. Fortunately, I am blessed with wonderful relationships with our children.

My Words of Wisdom for the Next Generation of Female Leaders

When I was 25, I was undertaking my PhD studies in chemical carcinogenesis, having decided a couple of years previously to change careers from my undergraduate studies in clinical psychology because I increasingly wanted to have a career that could make a tangible difference. I had no idea where my career would take me but found my PhD studies fascinating, and they led to my appointment as the inaugural post-doc at Australia's first children's cancer research laboratory. That laboratory became Children's Cancer Institute where I have spent nearly 40 years of my career. So my advice to myself at age 25, and to a new generation of professionals embarking on a career in child cancer research would be to go where opportunities take you and where you have a passion, be brave and take chances if opportunities come your way, and seek out people who will mentor and support you on your career journey. Our field has moved incredibly rapidly, with new treatments and cures possible where they never were before, and it is such an exciting time to be part of an international community committed to improving outcomes for children and young people with cancer. By thinking outside the box, and bringing people together, there is a solution to every problem.

MICHELLE HABER AUSTRALIA



JANICE NUUHIWA USA

Janice Nuuhiwa received her Bachelor of Science in Nursing at the University of Mary Hardin Baylor in Belton, Texas, and her Masters of Science in Nursing from Texas A&M, Corpus Christi.

She began her nursing career as a frontline paediatric nurse, which is where she found her passion for haematology/oncology nursing.

She has been engaged in her professional organization, the Association of Pediatric Hematology/Oncology Nurses (APHON), for over two decades and currently serves as President.

Throughout her career, she served as frontline staff in both in-patient and out-patient settings, nursing faculty, both didactic and as a clinical instructor, camp nurse, and Clinical Nurse Specialist.

She has participated in many medical mission trips across the globe. She is currently serving as a Nursing Professional Development Specialist at Ann & Robert H. Lurie Children's Hospital of Chicago, Illinois.

"Do what you can, with what you have, where you are" Theodore
Roosevelt

As a new nurse the haematology/oncology team at Scott & White Hospital in Temple, Texas, influenced my nursing practice by educating me to be respectful instead of fearful when caring for patients receiving chemotherapy. I was supported to attend a chemotherapy administration course created for adult oncology patients (APHON did not have a course at the time) and while excited, I was also overwhelmed. The nurse practitioners on the team took the time to educate me about the Paediatric Oncology Group clinical trials and, in turn, I created worksheets to assist the frontline staff with chemotherapy administration. This was pivotal in my career because I learned that curiosity blossoms into opportunities to learn and grow which positively impacts care. This set the precedence for advocating for my personal professional development.

Sue Walsh, DNP, CPNP, is my role model for being a good global citizen. She serves as faculty in a paediatric nurse practitioner program and many years ago called upon me to present on paediatric leukaemia and lymphoma. While serving as a regular guest presenter in her classroom, she shared about taking the students to Haiti for a specialized primary care clinical experience. Having done medical mission work myself, I was eager to participate. For several years, I was able to be a part of a team that went to Haiti every January. Serving in a low-resourced country was eyeopening and we learned how to provide care with limited resources. Our team was in Haiti during the devastating 2010 earthquake. There are no adequate words in the English language to articulate the awe I experienced watching Sue lead our team to compassionately care for the people of Haiti during this crisis. The experiences over the years created a professional awareness of the need to be a global advocate for care equality.

On Challenges and Overcoming Them

The challenge that greatly impacted my career revolved around compassion fatigue and how to mitigate it. I was not educated on how to care for myself, namely, my wholeness of character, as I cared for my patients and families and I was experiencing distress. This led me to search the literature to understand this phenomenon in nursing. Recognizing that this is an expansive gap for all nurses, and even more so for those who practice in oncology, allowed me to expand my career focus from paediatric haematology/oncology patients and families to focusing on paediatric haematology/oncology nurses with the goal of positively impacting the provision of high quality, safe patient care. Over the past several years, I have expanded my focus to be inclusive of all nurses at my institution.

Another challenge that shaped me as a nurse involved caring for a young adult oncology patient who survived a relapse only to be diagnosed with a secondary malignancy soon after her second remission. The team was zealously looking for open clinical trials and treatment protocols to offer to her when she informed us that she was "done." Her thoughtful decision about not pursuing treatment, instead choosing to die at home surrounded by her family, created in me a newfound awe for switching my internal monologue from "choosing to do nothing"—meaning "no treatment"—to embracing the decision to die on the patient's terms. For me, to witness her regaining control of her life, and, more importantly, her death, was a sacred experience. We never "do nothing." Sometimes, what we do is support our patients and families as they seek to experience a good death.

On Balancing Career and Other Life Responsibilities

I am not a fan of the term "work/life balance." I always wondered why the word "work" came first!Reframing that phrase to be "life/work integration" has been a gamechanger for me. Recognizing and honoring the fact that I am a human being with a life before I am a nurse, an educator, and a volunteer leader helps with setting priorities and shores up my internal resources so that I can continue this hard work, and heart work, we call nursing. This process is a reflective one that I need to engage with on a regular basis. It begins by asking myself what matters to me and what obstacles prohibit me from engaging in what matters. These questions, which come from the Institute for Healthcare Improvement's Framework for Improving Joy in Work, serve as a guide when reflecting on not just nursing hopes and dreams, but also on those in life.

My Words of Wisdom for the Next Generation of Female Leaders

If I had a chance to give myself advice at age 25, I would tell myself to slow down and be fully present instead of always focusing on the future. Don't miss those ordinary moments of joy while you chase those big goals. Engage in and enjoy being fully present with your patients, families, coworkers and in life in general. Find a reflective or meditative practice that involves nurturing your wholeness of character. Take good care of your physical, intellectual, spiritual, mental and emotional self.

JANICE NUUHIWA USA



AUDREY AUDREY EVANS UK/USA 1925 - 2022

Dr. Audrey Evans, born in 1925 in England, was a prominent paediatric oncologist, researcher, and advocate.

Her commitment to advancing the field of paediatric oncology saved many lives, and her advocacy for childhood cancer patients led to the establishment of vital support structures for patients and their families.

She received her medical education at the Royal College of Surgeons in Edinburgh, Scotland, where she was the only female student, and later earned a degree in Paediatrics at the University of Edinburgh in 1952.

It was during her medical training that Dr. Evans was exposed to the paediatric oncology field, igniting her strong commitment to fighting childhood cancer.

"A sick child is a sick family."

Career and Accomplishments

In 1953, Audrey Evans moved to the United States. With a Fulbright scholarship, she studied at Boston Children's Hospital under Dr. Sidney Farber, the father of modern chemotherapy. She finished her medical training at John Hopkin's University and started her career at the Children's Hospital of Philadelphia (CHOP), spending most of her career there. She quickly gained a reputation as a very skilled physician with a big heart who did things a bit differently. She is credited with the total care approach to patients, caring not just for their medical needs but also their spiritual, emotional and social needs. "A sick child is a sick family," Dr. Evans often said.

Over the years, Dr. Evans became a leading figure in paediatric oncology. She developed the Evans Staging System for neuroblastoma. This system helped standardize the diagnosis and treatment of neuroblastoma, which in turn led to improved outcomes for patients. She has been referred to as the "mother of neuroblastoma." She was among the first to combine and effectively use chemotherapy and radiation to treat neuroblastoma in children.

One of Dr. Evans' most significant contributions to paediatric oncology was her work on the <u>Total Therapy Study</u>, which led to a breakthrough in the treatment of childhood leukaemia. The Total Therapy Study combined multiple treatment approaches (chemotherapy, radiation, and bone marrow transplantation) to increase the survival rate of patients with acute lymphoblastic leukaemia (ALL). Previously, the prognosis for children with ALL was dire, but Evans' innovative approach transformed the survival rate from near zero to over 80% today.

Dr. Evans taught and mentored many students. "I met Dr. Audrey Evans when I was a medical student at the University of Pennsylvania, studying Paediatric Oncology," shares Dr. Kate Matthay, one of Dr. Evans' mentees. "She was a deep inspiration to me both as a strong, independent, clearly brilliant yet compassionate woman physician in the days when there were very few female medical students (my class had only 8% women). She took personal interest in teaching me many aspects of pediatric oncology, while also relating fascinating stories of her early training in Scotland. But most of all her work in neuroblastoma, a childhood cancer that fascinated me with its mixture of some lethal cases and others that spontaneously regressed, inspired my own lifelong career elucidating the biology and searching a cure for neuroblastoma."

Philanthropy and Advocacy

Dr. Audrey Evans was also a strong advocate for children with cancer and their families. Recognizing the need for support to families of childhood cancer patients beyond

support for medical costs, she co-founded the first Ronald McDonald House in 1974. The Ronald McDonald House Charities provide a "home away from home" for families with seriously ill children, where the family can stay close to the child while he or she is receiving medical treatment. There are 375 such homes around the world today.

Dr. Evans' advocacy efforts also extend to the realm of research funding. She co-founded the <u>Alex's Lemonade Stand Foundation</u>, which has raised \$200+ million for paediatric cancer research over the years.

Legacy and Impact

Dr. Audrey Evans' life and achievements have had a profound impact on the field of paediatric oncology. She improved survival rates for children with cancer and also contributed to a better understanding of the disease and the development of new treatments. She was a visionary in providing crucial support structures for patients and their families during some of the most challenging times in their lives. Her "efforts led to dramatically increased cure rates in a variety of childhood cancer, as well as establishing the infrastructure for all of the advancements made since. Her legacy in the field of pediatric oncology is unparalleled," said Dr. John M. Moris, CHOP, who worked with Dr. Evans for four decades.

Dr. Evans has inspired generations of paediatric oncologists and researchers to continue the fight against childhood cancer. After retiring from medicine, she established the St. James School in Philadelphia which provides excellent education for students in under-resourced neighborhoods.

Dr. Evans' life exemplifies the difference one individual can make in the lives of countless others. "I've had a great life," Dr. Evans was <u>quoted</u> saying. "I certainly have." She passed away peacefully at home in Philadelphia on September 29, 2022. She was 97.

AUDREY EVANS UK/USA



ZAINAB SHINKAFI BAGUDU NIGERIA

Her Excellency Dr. Zainab Shinkafi Bagudu, First Lady of Nigeria's Kebbi state, is a Pediatrician and Champion in the fight against cancer in Nigeria and beyond. She has contributed to improving cancer care in Nigeria, by making diagnostic equipment easily accessible and affordable through Medicaid radio-diagnostics. She is the CEO of Medicaid Radio-diagnostics and Medicaid Cancer Foundation.

The Medicaid Cancer Foundation (MCF) has contributed to spreading awareness on cancer and cancer advocacy through many initiatives such as community outreach programmes, school advocacy, authoring a book on the ABC's of cancer to educate the younger generation and hosting the biggest cancer walk in Nigeria annually. MCF also runs a "PACE" programme which supports cancer patients with access to free screenings, treatment support and patient navigation.

MCF has significantly contributed to the National Cancer control plan, Kebbi state cancer registry strategic plan for cancer and Cancer health funds at both National and State levels

Dr. Zainab is well known for her extensive philanthropy work across a range of causes.

On the global scale, she serves as a board member for the Union of International cancer control (UICC) and is currently running for President elect of UICC.

"The greatest
glory in living
lies not in never
falling, but in
rising every time"
Nelson Mandela

we fall

I've been fortunate to have relationships that have guided my decision-making process, all of which I am grateful for.

In school, I was heading for a career in mathematics, accounting or economics. However, my uncle who took me to register for my pre degree course colluded with the then Vice Chancellor and opined that due to the lack of female doctors in Northern Nigeria, and considering I had achieved the entry requirements for a degree in Medicine, I should change my entry.

7 years down the line whilst in my first Paediatric rotation, I met a registrar who would turn out to be my second inspiration. He questioned me relentlessly. At the time, I felt picked on. Even when I gave the right answers, he wanted more. So I looked for more. I put in extra hours ensuring I knew each patient on the ward at all times and details of their diseases. Although I was doing it to avoid being embarrassed on rounds, it made me understand and love Paediatrics as a speciality and made my choice easier. By seemingly picking on the shy girl at the back, my registrar helped me break barriers, excel and make a vital career choice.

Additionally, I've been able to be a part of various professional networks and communities that have helped me expand my knowledge and skills. These groups have provided opportunities to connect with like-minded individuals, share ideas and resources, and learn from industry experts.

Finally, I believe that learning from clients, patients, and survivors has been instrumental in my career development. Their feedback and insights have challenged me to think out of the box and adapt to new situations, and as a result, improve my work.

On Challenges and Overcoming Them

As a medical doctor who has set up a diagnostic facility in Nigeria, I have encountered several hurdles along the way.

- Nigeria has a shortage of skilled healthcare professionals, particularly in specialized fields such as radiology, oncology and pathology. Professional flight to greener pastures (high income countries) makes it difficult to retain qualified staff, which in turn can impact the quality of services we offer.
- Obtaining the necessary licenses and permits can be time-consuming and expensive, and failure to comply with regulations can result in fines or even closure of the centre.
- The healthcare sector in Nigeria is becoming increasingly competitive, with new entrants constantly emerging.
 This means that my team and I must work hard to

- differentiate ourselves and attract patients, which can be challenging in a market that is already crowded.
- Multinationals and manufacturers generally do not extend credit lines, worthwhile finance packages and offers for long/short term equipment lease to LMICs in Africa. Poor national credit histories and political instability mean that those of us running businesses that would benefit from such have to buy outright using high interest rates.
- Many people in Nigeria believe that cancer is a death sentence and are unaware of the available treatment options. The level of knowledge is still very poor. In my community it's called "Ciwon Daji"- disease of the forest. Indicating a condition that belongs isolated, away from human contact and ostracized. Many are reluctant to talk about cancer or seek medical help due to the fear of being ostracized by their communities.

My role as First Lady in Kebbi states gives me access to people in very rural and hard to reach areas. Despite these challenges, I remain committed to raising awareness about cancer, providing support to cancer patients and survivors, and advocating for better cancer care in Nigeria and beyond.

On Balancing Career and Other Life Responsibilities

In the span of 4 decades, from studying and practicing medicine to setting up a multi diagnostic centre alongside a cancer non-profit organisation. It's been a challenging but extremely fulfilling journey. As the years pass, professional and personal responsibilities both grow — sometimes too quickly to manage. Maintaining a strong and well-informed team at work is critical for optimal productivity. Being successful means reaching the goals you set in all aspects of life, from signing on high-net worth clients to attending open days in your Children's school. Getting it right is a process that requires some trial and error. It's important to be patient with yourself and to keep experimenting until you find what works best for you.

My Words of Wisdom for the Next Generation of Female Leaders

Take care of your physical, mental and spiritual health: Regular exercise was not a part of my life till I was 50. The impact on my output has been amazing and I regret not starting earlier. I have strong bonds with my family and childhood friends and the support they provide is irreplaceable. Build your professional network. By engaging colleagues, mentors, and others in your field. Attend conferences and events, join professional organizations, and try to follow up on contacts. Don't be afraid to take risks and try new things. Be open to new opportunities and challenges, and always be willing to learn and grow. It's also important never to feel too proud to seek professional help. There will be testing times.

ZAINAB SHINKAFI BAGUDU

NIGERIA



NUBIA MENDONÇA BRAZIL

Dr. Nubia Mendonça is a Paediatric Oncologist who has served as the Chief of Department of the Pediatric Oncology Center at Martagão Gesteira Hospital and as President of the Brazilian Society of Paediatric Oncology.

She was born in 1944 in Brazil.

In 1968, she graduated with a degree in Medicine. She then studied Paediatrics and Clinic Laboratory in São Paulo. In 1972, she went back to the Brazilian State of Bahia and began working at Martagão Gesteira Hospital.

In 1976, she contributed to creating the first Pediatric Oncology Center at the same hospital. As a consequence, she went to Buenos Aires, Argentina, to study that specialty.

When she returned, she was nominated as the Chief of Department.In 1978, she moved to Paris and studied under Dr. Odile Schweisguth and Prof. Jean Lemerleat at the Institut Gustave Roussy.

In 1979, she went back to the city of Salvador and continued her work there until 2011.

"Be courageous, be empathetic, and stay qualified."

Many people had a big influence on me throughout my life. First, my parents—by their example of love, generosity and kindness. Furthermore, during my medical path, I had a professor who impressed me: Prof. Dr. Antonio Jesuino Neto. I had the chance to work with him at two different hospitals, and it was such an extraordinary experience. We treated people who had urgent situations and his manner of listening to the patients, examining them and explaining their diagnosis was something to learn and I reproduced his approach in all my medical life. We also went to the patients' houses occasionally and we could see by ourselves their state of poverty; nevertheless, Prof. Neto would listen, examine and give the right diagnosis with the same kindness. Additionally, above all, he would take into consideration those patients' income when prescribing medicines and drugs that were affordable. He is still my reference.

The second person who was influential during my studies in Paediatrics was the Chief of Fellows, Dr. Maria Clara Faria, at Red Cross Hospital in São Paulo .She knew Paediatrics like no one else, and we had daily meetings with her where we discussed the patient cases. She prepared us how to begin coming up with a diagnosis, and, by elimination, how to reach the correct diagnosis. At the same time, she trained us to give lectures, to discuss our patients in medical sessions and, above all, to listen to every word that a mother or a father of a patient told us, paying much attention, giving value to their words and examining with much care.

On Challenges and Overcoming Them

My first challenge was when I was nominated to serve as the Chief of Department of the Pediatric Oncology Center at Martagão Gesteira Hospital. The service was the first one in the North and Northeast of Brazil and our state had at that time 10+ million citizens. Our patient load was big. The service had 32 beds distributed in 4 infirmaries and 2 apartments for patients who needed to be isolated. As we expected, in a short time, our service became the biggest in our region and the third in number of cases in our country. For me, it was a big challenge because I had studied just two months, at Hospital de Niños, in Buenos Aires, under the supervision of Dr. Angela Cebrián Bonasena, Dr. Enrique Schwartman and Dr. Frederico Sackmann Muriel. I studied a lot when I came back and I worked with my fellows which helped me very much.

The second challenge was when I became President of the Brazilian Society of Paediatric Oncology in 1985. Our Society was relatively small and members didn't know each other. With my colleagues, we began finding ways to get everyone acquainted with each other, from those working in the small service centres to the those in the biggest ones. We achieved that in two years. I was President for 3 more years. Finally, we consolidated our Society as the biggest

one in Latin America.

Those 2 challenges made me know that when we really want something, we can achieve our objectives. Sometimes, with more effort, other times, with less, but, we can't give up. Life prepares challenges and hurdles to teach us ways of progressing and how we can become stronger. I learned very much from those 2 experiences.

On Balancing Career and Other Life Responsibilities

Since I was 5 years old I said that I would be a doctor. During all my life, I didn't change my mind. So, when I was 18 years old, I began to study Medicine, but I didn't know what specialty I should do. I studied a lot and I was the best student in my group. When I was in my last university year, I decided to become a Paediatrician. This decision was influenced by Dr. Jamal Wehba, a fellow at that time, who showed me the beauty of being a Paediatrician.

I didn't think very much about my private life back then because the only thing that I desired was to be a good doctor. So, I went to São Paulo to study Paediatrics at Red Cross Hospital. At that hospital, I saw for a first time children with cancer (leukemia, lymphoma and solid tumors), and that was tough for me.

I didn't think about marriage or other life responsibilities. I just thought about Medicine. I worked hard. And I was very happy back then. Moreover, I was never worried about balancing my life and other life responsibilities. And, I didn't have to justify my choices in life. I continue being single, without any children.

My Words of Wisdom for the Next Generation of Female Leaders

The advice that I would give myself at age 25 is to continue studying hard, to continue looking up to people such as Dr. Maria Clara Faria and trying to be a good doctor. Life made me decide to study Paediatric Oncology when I was 32 years old, by chance, influenced by my first Paediatric Oncology service in Bahia.

So, for the younger generation of professionals who want to be Paediatric Oncologists, I would say: be courageous, be empathetic, and stay qualified. It's a long way to go, you will find moments of success, but there will also be times of sadness when we can't save our patients. But, don't give up! When you will get older, you'll have a lot of experiences to tell to the younger doctors and fellows and you'll see that you made the difference in the lives of a lot of families. You 'll be happy!



SALMA CHOUDHURY

BANGLADESH

Salma Choudhury is Founder Chairperson of ASHIC, (A Shelter for Helpless III Children), a nonprofit charitable organization for improving the Survival Rates of the Cancer Fighters in Bangladesh.

Salma completed her college education in 1972 and got married that same year. In 1992, her youngest son, Ashiq, was diagnosed with cancer. His sudden diagnosis, prolonged treatment in London and eventual death at age 3, brought a calamity into her family's life.

During her son's treatment, Salma came across the miseries of many children and their families. She also experienced the activities of benevolent societies, charity organizations who offered comfort to these children during their darkest days.

After the loss of Ashiq, Salma was inspired to stand next to the cancer warrior children of Bangladesh. She transformed her thoughts into reality by founding the Shelter for Helpless III Children (ASHIC), a charity organization dedicated to improving the quality of lives for children with cancer.

Salma has attended many international seminars, symposiums and training programmes at home and abroad. As a member of Childhood Cancer International (CCI), she regularly attends SIOP and CCI Congresses in various locations of the world as a selected speaker.

She is now working actively with 11 different needbased programmes for Childhood Cancer in Bangladesh.

"Together
we can
fight against
childhood
cancer."

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WOMEN LEADERS ALMANAC

My biggest influence is my youngest son, Ashiq Husain Choudhury, whom I lost to cancer when he was only 3 years 3 months and 3 days old. Since that fateful day on May 20, 1993, I rose up to keep the memory of my son alive through the activities of ASHIC, which aims to improve the survival rate, give quality of life to, and reduce the sufferings of the cancer warrior children and their families living in Bangladesh.

Another person is Dr. Cynthia Goh of Asia Pacific Hospice Palliative Care Network (APHN) in Singapore, who was a pioneer in palliative care in the Asian Pacific region. Our primary bond was as bereaved mothers. When I first visited her in 1995, I mentioned to her how my depression from losing my son Ashiq had propelled a housewife into starting ASHIC. At her invitation both ASHIC, and I personally, became members of APHN. Cynthia's high quality work with her Palliative Care team prompted me to request her to come to Bangladesh and teach our medical community about the practice. She gave trainings from 2013 till 2018, twice a year for 5 days. As one of the organizers of the 2004 SIOP Asia Congress in Bangladesh, at my invitation Cynthia and her colleague Rosalie Shaw held a session on palliative care, which was well received. In 2005, when ASHIC received grants from UICC and Sanofi-Aventis to establish Bangladesh's first Palliative Care Unit (PCU), the first person I gave the happy news to was Cynthia. With her guidance, I designed the ASHIC PCU to be a South Asian center of excellence for palliative and holistic care for our cancer warriors. We have also presented the programme at CCI/SIOP Congresses as a replicable model for other developing countries. Since her passing in 2022, I miss Cynthia greatly.

On Challenges and Overcoming Them

ASHIC is the first non-profit charity organization dedicated to serve and improve the quality of life to the cancer warrior children by providing hope, physical and emotional support through conducting 11 different need-based programmes in Bangladesh.

As a pioneer in the field, we faced much resistance. Especially, when we established a Palliative Care Unit, it was totally a new concept in Bangladesh in 2006. We had to redirect a significant amount of funding towards unanticipated awareness raising programmes so that doctors would prescribe palliative treatment over curative treatment for terminally ill patients. The active collaboration paid off and now palliative treatment is an integral part of the care system for the cancer warriors.

Another challenge was to establish an accommodation facility for cancer warriors. In 2000, ASHIC Shelter was established in a rented house. It was the first "Home Away

from Home" facility in Bangladesh for children coming from rural area for treatment in the capital city of Dhaka. The Shelter plays a pivotal role in improving survival rates. However, many landlords refuse to rent facilities when they understand the kinds of children we serve, with their risk of death. Later in 2018, ASHIC Shelter opened doors for the cancer warriors in ASHIC's own property. The Shelter is equipped with 20-bed free accommodation facility which is within 2 km of Bangabandhu Sheikh Mujib Medical University (BSMMU) Hospital, the Primary Pediatric Oncology Hospital. Families are motivated to complete the treatment protocol which is the direct positive impact on survival rates. Now there is widespread recognition and support for both programmes.

On Balancing Career and Other Life Responsibilities

I started my career at 40 becoming a dedicated social worker from being a housewife. By then, my surviving children were all grown up. Work life balance was not so difficult. My husband, Mr. Afzal Husain Choudhury, who is a life-long entrepreneur, was my great support and inspiration. He is also the Founder President of ASHIC, which he conceptualized as a way to bring me back to life after the loss of our son. I can never forget the support of my daughter Maheen Hamid, who was deeply affected by the loss of her brother. She started helping out with ASHIC from a very young age with a profound desire to help improve the chances for the disadvantaged cancer warriors in Bangladesh. As the Director of Outreach and Content Management, she plays an important role in establishing the strategic direction for ASHIC, including its fundraising and marketing initiatives. The continuous support of my mother works as a strength for me. I am grateful to the Almighty for the blessing I received to continue my work.

My Words of Wisdom for the Next Generation of Female Leaders

I would tell my 25-year-old self, "Never underestimate the power of motherhood. It can move mountains." Pediatric Oncology chose me as its ambassador once I lost my son at age 40. Otherwise, this field might have been neglected for longer in Bangladesh. My mother's heart couldn't bear the suffering of another child or mother, and I found my healing in the work we do.

Childhood cancer is a very sensitive and touching field. In our country, very few children can survive. I would encourage the young generation of professionals who are just now embarking on a career in Pediatric Oncology to consider doing research on Childhood Cancer and help create an accurate database of the real scenario in Bangladesh. With a focus on improving survival rates to reach Western standards, the youth has the opportunity to define new career paths.

SALMA CHOUDHURY

BANGLADESH

NOTES



INTERNATIONAL SOCIETY OF PAEDIATRIC ONCOLOGY

SIOP continues to be at the forefront of education and research in paediatric oncology.

SIOP has over 3,000 members worldwide and its Annual Congress is typically attended by 3,000+ healthcare professionals from 110+ countries.

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- Eligibility for SIOP scholarships and awards
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- Opportunities to learn from and exchange knowledge with other pediatric oncology professionals
- Eligibility to run for office and to vote for SIOP Leadership Positions

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