



EDITH GRYNSZPANCHOL ARGENTINA

Edith Grynszpanchol is a bereaved mother of Natalí, who died from cancer at the age of 9. At that moment, she had three other kids. Two years after Natalí's death, she gave birth to another baby. Nowadays, she is also a dedicated grandmother of 7 kids.

Soon after Natalí's death, she knew that she could not stand without doing something that could benefit others, doing something for the betterment of others' life. With a group of friends and family, she founded the Natalí Dafne Flexer Foundation (FNDF) in her memory.

FNDF provides direct services to more than 1,200 families each month in its 10 locations in Argentina. It is active in other levels of intervention with Doctors, Nurses, Psychologists, Schools and in Research. FNDF established direct relations with Governments and Authorities and generates Advocacy actions.

She is involved in the National, Regional and International work through different Networks: the National Network of Organizations helping children with cancer in Argentina, and the Psychosocial Chapter of the Latin American Society of Pediatric Oncology. For 13 years, she represented Latinamerica as a Board Member of the CCI. She is a member of the new Essential Medicines Working Group at the SIOP, which collaborates with the WHO Global Initiative.

**Be aware that
you serve the
families; trust
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best for them!**

On Relationships that Influenced My Career

I am thankful to Dr. Enrique Schwartzman, a very well-known Argentinean oncologist, who trusted in me and taught me everything I needed when I started the Foundation. He also believed that I could understand the medical issues that will influence and shape real access to treatment, the challenges we will face, at that point, and in the future.

The other person who was very influential was my father, with whom I worked in his industry. He showed me “in practice” the value of not feeling economically dependent, to keep the freedom to function as it is needed: no convenience guiding the decisions. It was especially important in the Foundation’s development as a very transparent and independent organization.

On Challenges and Overcoming Them

The services that the Natalí Dafne Flexer Foundation provided proved, very early, to be very useful and were requested not only by families, but also by Doctors and other institutions. The challenge at that moment was translated into the fact that the Foundation went through a crisis of growth. Not every person in the organization agreed with the changes needed and, on the other hand, the fear was of losing control of the development and the “depersonalization” and loss of quality of the services given to families. It was my personal decision to go forward with the changes, slowly and one by one and I sought continuous advice from qualified professionals. Now, we deliver services to more than 1,100 families each month throughout Argentina.

Because of my character, I was asked to be part of the National Government of Argentina. At first, I accepted and worked from the beginning on Health issues. Soon, I realized that I didn’t know “how to play this sport” when I did not agree with the way they manage the situations and the time it took.

From that moment, I have very clear mind that there is no way to be directly involved, for me. We have now a clear policy on the relationship with Authorities and Governments at national or regional levels and also with the Pharma and other Industries.

On Balancing Career and Other Life Responsibilities

As a bereaved mother, I had a personal and deep relationship with my work that did not allow me to take my time for personal desires, other than taking care or sharing time with my other kids and, afterwards, my grandchildren. I thought that surviving Natalí was only possible if I dedicated the rest of my life to her memory. Despite her illness and her own situation, she showed a strong empathy to other kids in treatment. She was very sensitive.

I used to work 24/7 for almost 20 years, until I started extraordinarily strong Psychological Therapy. Only then I could think of myself as someone other than “Natalí’s mother.” Then, I started to take care of myself, my physical wellbeing, doing Gym and Sports. I returned to my passion for Photography and travelling. I am also learning to edit the pictures I take and starting to digitalize and prepare albums of the thousands of printed pictures I have taken during my kids’ childhood.

Definitively, taking it seriously and putting effort during many Therapy Sessions opened the door to my inner desires of living a meaningful life and enjoying being alive, again.

My Words of Wisdom for the Next Generation of Female Leaders

Be aware of families that you serve, trust that you are going to do the best for them. Thus, there is nothing that can be out from the scope of your organization, in terms of access to treatment and care and quality of life.

The Foundation needs to know and understand your local situation and the forces that sustain the positive situations and those forces that promote and sustain the negative ones, in order to plan advocacy actions and generate systemic changes. I wish I knew and understood it earlier.

There are internal processes, from the procurement to the delivery of medicines, that contribute to effective access to quality medicines, for example. The Foundation needs to know and understand that chain, why it is designed in that way, the responsible people involved and, sometimes, the ridiculous steps and requirements. The ideal is to propose specific changes or suggest which steps the health system can suppress.

It is a substantial change in the role of the helping organizations, to be no longer seen only as an emotional aspects' guardian or just a resources provider, but an influence player within the Health System.

As an Ashoka fellow, I had a dedicated advisor, and we worked together for an extended period on understanding the concept of Systemic change, learn how to analyze a System' forces and behaviors and, then, thinking on how to generate systemic changes.