



Challenges in Developing Pediatric Cancer Care in Armenia

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Parallel Worlds

When I was born, pediatric cancer was considered incurable in Armenia. It was 1987.

In the same year, Steinherz from Cornell wrote in his manuscript that “over the last 20 years, the rate of long-term disease-free survival of childhood acute lymphoblastic leukemia increased from less than 1 to 60 per cent” (Steinherz 1987).

When I entered medical school in 2004, the survival rate of pediatric acute lymphoblastic leukemia (ALL) in Armenia was already close to 65% (Danielyan 2009; Danielyan and Iskanyan 2004). At that very moment, I even did not know what leukemia is; that word was familiar to me only from a South American soap opera, and in my memory, it was associated with a beautiful girl, who was bald and sometimes sad.

According to the World Health Organization (WHO), in the high-income countries (HIC), the survival rate of pediatric cancer is around 80%,

meaning that four out of five children with cancer survive. However, in the low- and middle-income countries (LMIC), the situation is opposite, meaning that four out of five children with cancer die (Childhood Cancer n.d.).

On February 15, 2021, on the International Childhood Cancer Day, I gave an interview and reported a survival rate of pediatric cancer in Armenia close to 75% (Tamamyán 2020; Hovhannisyan et al. 2020; Papyán 2018). To me it was an achievement, achievement of hard work and dedication of a beautiful team of doctors and nurses, who made this happen. Armenia, a developing country with very limited resources, is reporting pediatric cancer survival close to the HIC. Currently, I am fortunate to lead the only institution in Armenia treating children with hematologic and oncologic disorders; that wonderful team made this miracle happen. But 17 years ago, at that very moment, I even could not imagine that one day, in one of the early Armenian mornings, I would be sitting in the office of the Pediatric Cancer and Blood Disorders Center of Armenia and writing this chapter about the challenges and achievements of pediatric cancer care in Armenia.

In this chapter, I will try to present the work of the generations of pediatric hematologists and oncologists, who made the treatment of pediatric cancer care in Armenia a reality, about the challenges and hardships and about the achievements and future plans.

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From 0.7% to 80%

Armenia is a small country in South Caucasus, with a population of three million. For several thousand years, starting back from Noah, Armenians have been living on this land and throughout the whole history of humanity experienced many rises and falls. The current Republic of Armenia declared its independence in 1991, after the collapse of the Soviet Union (Wikipedia: Armenia [n.d.](#)). The devastating earthquake of 1988, which destroyed the whole northern part of the country and killed more than 38,000 people, the Nagorno–Karabakh war, thousands of refugees, closed borders, and collapsed post-Soviet economy contributed to the situation when in 1992–1994, several pediatric hematologists at the Hematology Center named after Prof. R.H. Yeolyan (previously called Scientific Research Institute of Hematology and Blood Transfusion) started thinking about doing multiagent chemotherapy for children with leukemias.

Dr. Samvel Danielyan, a newly appointed chief of the pediatric hematology department, returned from Moscow and, together with the medical and nursing team of the department, started the German BFM treatment protocol for children with ALL. Lack of cancer medications, supportive care agents, and infusion pumps and limited electricity, water, and blood supply are the contributing factors which were guarantees for the failure. But, as it was well said, where there is a will, there is a way, and children started getting into remission and more and more started getting cured.

Recently, it was published that from 1982 till 1994, only 3 (0.7%) out of 430 children with ALL in Armenia survived, but after the implementation of BFM protocol, between 1994 and 2019 years, 502 (73.3%) out of 685 children with ALL conquered leukemia (Danielyan et al. [2020](#)). The results were impressive and comparable with the results from the Western developed countries.

Therapeutic treatment of patients with pediatric solid tumors was organized at the National Oncology Center, as well as the radiation therapy

department that was located there. Surgeries were performed in several public and private pediatric hospitals.

In 2008, part of the team led by Dr. Danielyan, involving also young physicians just after completing fellowship training, moved to the Muratsan Hospital of Yerevan State Medical University, where not only children with hematologic malignancies but also children with solid tumors started getting treatment according to the internationally recognized treatment schemes. This, in turn, led to better outcomes in this group of patients. A recent analysis from Muratsan Hospital showed a 5-year overall survival close to 80% (Tamamyan [2020](#); Papyan [2018](#)).

Entering a New World

In September 2010, I walked the doors of the Clinic of Chemotherapy of Muratsan Hospital of YSMU as a first year fellow of hematology. At that time, we did not have a separate fellowship program for pediatric hematology–oncology. So, to treat children with cancer, you had to finish either the hematology (3 years) or oncology (2 years) fellowship program, which included both adult and pediatric parts. Childhood leukemias were the most interesting for me, so I chose the hematology fellowship, but doing it at the oncology department led by Dr. Danielyan.

The clinic was on the first floor of a pediatric academic hospital on the edge of Yerevan City. It was handed over to the university several years ago and had been actively in the reorganization and construction processes. The chemotherapy clinic had both pediatric and adult practices, so physicians were treating children and adults with different malignancies. Opinions were different about a joint pediatric and adult clinic. Some were saying it was a bad idea to have them together; others were saying the opposite, especially after seeing happy faces of adult patients after the interaction with their new little friends. But I can surely say, at that very moment, it was a very productive cooperation and led to major changes in the cancer care in Armenia.

During my student years, I had classes in majority of the hospitals in Armenia, but the Muratsan Hospital and the Clinic of Chemotherapy were something different. The atmosphere, the team, and the dedicated people—all these were making this place unique. In Armenia—and I am sure in many other developing countries—cancer is stigmatized, and the majority of people associate it with a death sentence. People visit cancer centers very depressed and sad, but one thing I clearly remember from Muratsan is that people were telling that this clinic is different that you get so much positive energy there.

This positive energy caught me as well, and from the first moment I entered the clinic, I became part of Muratsan and part of that exceptional team.

Getting Around the Globe

Besides being a team, where every member was helping each other, the Muratsan team also was very active on getting training outside of Armenia. Dr. Danielyan had always been telling that we needed to see the world and to observe and learn how people practice medicine in the other countries—this would be the only way to become a good specialist and to improve our field of medicine in our country. Not surprisingly, it was not a common practice in Armenia, and I think in many other developing countries, to encourage your team members to get around the world and invest in education. Usually it is opposite; supervisors try to oppress the youngsters, thereby often eliminating the future competition.

When people ask me “What is the key for your success?” I would always say without any hesitation that I was fortunate to have the best mentors one could imagine, and this was true starting from Armenia going to the USA, Germany, Taiwan, Austria, and Belgium.

During the recent 10 years, I do not remember a single day, when I was not a student. Currently, I am leading a pediatric cancer center, chairing a department at the medical university, and just recently got a full professorship, but right now

also, I am a student, studying global health diplomacy at Toronto University (Canada).

For me education has never been just merely a knowledge gaining process but also a way of exploring the world, becoming acquainted with people, interacting with them and using the knowledge and skills, and, most importantly, networking to improve the cancer care in my country.

It has been a long journey for me—visiting fellowships in pediatric hematology/oncology at the Children’s Hospital of China Medical University (Taichung, Taiwan), St. Anna Children’s Hospital (Vienna, Austria), master’s program in advanced oncology at the University of Ulm (Ulm, Germany), PhD fellowship in oncology at YSMU (Yerevan, Armenia), postdoctoral fellowship in the leukemia department at the University of Texas MD Anderson Cancer Center (Houston, TX, USA), medical research fellowship at the European Organization for Research and Treatment of Cancer Headquarters (Brussels, Belgium), visiting scientist at the Dana–Farber/Boston Children’s Cancer and Blood Disorders Center (Boston, MA, USA), High-Impact Cancer Research postgraduate program at Harvard Medical School (Boston, MA, USA), observership at St. Jude Children’s Research Hospital (SJCRH) (Memphis, TN, USA), Global Health Delivery Intensive Course at the Harvard School of Public Health (Boston, MA, USA), and countless of seminars, conferences, and short trainings.

During and after every program and training, we were making a new step and organizing a new program, and when looking back, I can state that these programs were life-changing experiences.

Difficulties and Victories

In December 2015, I returned back home. I packed my big baggage to the airport in Boston and then made a few days stop in Orlando for the American Society of Hematology annual meeting, and in a winter day, I landed in Yerevan, my home city.

Why did I return? For two reasons: first, because it is my home, and second, because I was confident that I could make a change. Was it a difficult task? Definitely, it was. Were we able to make a change? Definitely. We were fortunate.

I started working at the Muratsan Hospital of YSMU, at the clinic where I made my first steps in pediatric hematology and oncology, and also lecturing at the oncology department of YSMU.

Of course, there were people who were making obstacles, but altogether, there were always those who were helping to overcome those challenges. One thing I know for sure and I believe in firmly is that if you want something very much, the whole universe will help you to achieve it.

I will try to summarize the achievements we accomplished during the last decade, hoping that these steps could be educational for others.

In 2012, we founded the Armenian Association of Hematology and Oncology (AAHO), the professional union of cancer and blood disorder specialists. Since that time, our team organized and hosted large and small educational and scientific events, which had a significant impact on Armenia. To name few of them are as follows: first American Society of Clinical Oncology (ASCO) Multidisciplinary Cancer Management Course in Armenia, first ASCO joint master class with the European School of Oncology and Pediatric Oncology East and Mediterranean Group second Scientific Congress, first Cancer Survivorship Congress in Armenia, “Conquering Cancer in Armenia with a Smile” International Conference with the MD Anderson Cancer Center and Dana–Farber/Boston Children’s Cancer and Blood Disorders Center (DF/BC), first Taiwan–Armenian Medical Congress, International Society on Thrombosis and Haemostasis first Educational Course in Armenia, and many others.

In 2014, our team of physicians founded the City of Smile Foundation (CSF), which later became the largest cancer charity in Armenia and currently is covering the whole diagnosis, treatment, and care for children and young adults from 0 up to 25 years old in Armenia. The founda-

tion also puts much effort in research, capacity building, education, and development. The initial purpose of the foundation was for every cancer patient in Armenia to receive appropriate care regardless of their or their family’s financial ability, but later on, the foundation extended its scope. In 2016, with the help from DF/BC, we established the first psychosocial program for cancer patients in Armenia. The program became much larger during the time and now is a well-functioning and important part of our center. In the same year, AAHO signed a memorandum with MD Anderson Cancer Center, which enabled many specialists to get training there and also to start joint research.

In 2016, we started the cancer.am website, analogous to cancer.net, which contains specialist-approved information for the public. The creation of the website was supported by the US Embassy in Armenia and became an important tool for patients, caregivers, and the whole public.

Starting from 2016, with the support from the World Vision, we started training rural pediatricians and GPs in pediatric oncology. For that, we also translated the WHO-PAHO (Pan American Health Organization) guide for the early pediatric cancer diagnosis. Due to this training and the guide, more and more physicians started referring the patients in the early stages.

In 2018, Dr. Danielyan was appointed as a director of the Hematology Center after Prof. R. H. Yeolyan, and this was the catalyst that later in February 2019, we were able to merge all the existing pediatric hematology and oncology units in Armenia and to create a united Pediatric Cancer and Blood Disorders Center of Armenia (PCBDCA), which became part of the Hematology Center, renovated in 2016.

In 2019, Armenia became the first country to join the St. Jude Global Alliance led by the SJCRH. With St. Jude, we have had a long-lasting relation, but this further catalyzed our cooperation (Armenia Becomes First Country to Join St. Jude Global Alliance [n.d.](#)).

From the same year, with the support from the Bridge of Health charitable foundation, we

started working on the creation of a pediatric cancer registry for Armenia. We went back up to 25 years and started scanning all the medical documentations from every single unit in Armenia, who had a patient with cancer. Later on, we started extracting data from those pdfs and putting in the St. Jude Global Registry. Even though this is a huge amount of work, it will give us very valuable information about the past and the present of pediatric cancer care in Armenia and will help to shape the future.

Another critically important milestone was the establishment of the Department of Pediatric Oncology and Hematology at YSMU in July 2019. We created a 3-year fellowship program for a united “pediatric hematologist–oncologist” specialization and for the first time in the history of Armenia accepted fellows for training in this specialization. For our fellowship program, besides the general requirements, we put special requirements: knowledge of foreign languages (at least English and Russian) and a mandatory requirement of doing a research and publishing a paper in internationally recognized scientific journals. This decision allowed us to accept the best graduates of our medical university. In the first year, we got seven fellows and the next year three fellows, from which one is from Russia. From the first days, fellows got actively involved in the clinical work and started doing research. Already in the first year, 35 abstracts were submitted and accepted at major international congresses. This was a big achievement for a small country like Armenia with such a small field like pediatric hematology–oncology.

In August 2019, we made another important decision on the creation of four multidisciplinary working groups (WGs)—leukemias, lymphomas and SCT (stem cell transplant), solid tumors, neuro-oncology and musculoskeletal tumors. This initiative was supported by the CSF. Each working group has been discussing all cases in a multidisciplinary setting on a weekly basis, involving also foreign experts. In addition, every WG started translating and adapting guidelines for different cancer subtypes. By the end of the first year, we had created already guidelines for 17 cancer subtypes (overall, around 4000 pages

of work), which included a manual for specialists, a manual for primary healthcare providers, and a guide for the patients. This helped us not only produce the guidelines, which was really a unique effort for our country, or have multidisciplinary meetings, but it was a great help for all our staff to update the knowledge and develop their English language skills. We recruited a full-time coordinator for each WG, with medical or public health background. I should state that this step was critical for the success of the project, to have dedicated personnel for coordination. All the members of the WGs were salaried; since the salaries for medical personnel are very low in Armenia, this was also a kind of a salary supplementation and incentive.

Palliative care is an essential part of the cancer care, but it is greatly lacking in our country. In the coming month, we will open the first pediatric cancer palliative care center (hospice) within the PCBDC, which is a beautiful five-room facility with international standards. It was constructed by the support of CSF. There were many other achievements in recent years, including starting doing high-dose methotrexate for leukemias, brain tumors, and bone sarcomas (5 g/m² and more), special training for nurses, active work within international organizations, etc., and with every achievement, of course, there are many difficulties to get there.

Of course, pediatric oncology is a sensitive field. Many people want to help kids with cancer, but when you do some good thing, there are always people, who seem to put hurdles in your way. The phenomenon of small countries is that huge problems can be solved in a minute, but sometimes to solve a tiny problem might take ages and enormous efforts.

Recent years were very productive years, but still there is a lot to do. During a recent interview with a local journalist, I was asked what my dream was, and I responded that no child with cancer would leave Armenia for getting treatment abroad, but just the opposite, children from abroad would come to Armenia to get a high-quality care. Of course, this is a difficult task, but I am sure that day will come. During my not very long career, I understood one thing very clearly

that everything is achievable; you just should be persistent and do not pay attention to negative people.

Epilogue

It is Saturday afternoon, March 6, 2021, 26–27 years ago, the same days Dr. Danielyan was sitting in the reception of different business people and authorities, asking for pediatric cancer medications. The majority of those meetings ended with zero results; it was very disappointing. But he was persistent, and the day came. With several kindhearted people, the Hilfe für Armenia Foundation was established in Germany to help children with leukemia living in Armenia. For more than two decades, this foundation became the cornerstone for advancing pediatric leukemia treatment in Armenia, helping to cure more than 1000 children with leukemia.

A long time passed, those children with leukemia now have their own children, but, unfortunately, like in the 1990s, the government is not covering the diagnosis and treatment of these catastrophic diseases. Hence, the physicians need to think not only about medicine but also about making the medicine accessible.

And now I am sitting in the room, in front of the laptop screen and sending emails to the people around the world. I do not know most of them. I found their names in the list of philanthropists of Armenian and foreign organizations, churches, and community organizations. The majority of them do not have a publicly available email, and it usually takes time and efforts to get any contact from them. And in the early morning, when they wake up, they are going to open their mailbox and find an email entitled “Help request for pediatric cancer patients

in Armenia” from a person from Armenia, about whom they have never heard. Most of them will not answer to this spam-like email; few of them will reply but will regret about not being able to help, and only one or two answers from tens (sometimes hundred) of emails will be positive! But those positive emails definitely will come; one just needs to be persistent and not give up. And those 1–2 emails will be the catalysts of change!

References

- Armenia Becomes First Country to Join St. Jude Global Alliance (n.d.) <https://www.commercialappeal.com/story/news/2019/04/12/st-jude-childrens-research-hospital-st-jude-global-alliance-armenia-childhood-cancer/3445747002/>. Accessed 10 March 2021
- Childhood Cancer (n.d.) <https://www.who.int/news-room/fact-sheets/detail/cancer-in-children>. Accessed 10 March 2021
- Danielyan S (2009) Treatment achievements, challenges and perspectives of childhood leukemias in Armenia. *New Armen Med J* 3(3):91
- Danielyan S, Iskanyan S (2004) Treatment outcomes of childhood leukemias after the implementation of BFM program. *Med Armen* 44(1):86–87
- Danielyan S, Vagharshakyan L, Zakharyan A, Iskanyan S, Arakelyan S (2020) Increasing the effectiveness of treatment among children with leukemia in the Republic of Armenia. *Eurasian J Oncol Clin Med* 1:39–42
- Hovhannisyán S, Papyán R, Sargsyan L, Danielyan S, Vagharshakyan L, Avagyan A et al (2020) Pediatric cancer care in Armenia: the results of a qualitative analysis. *J Clin Oncol* 38(Suppl):abstract e19002
- Papyán R (2018) The state of pediatric oncology in Armenia: challenges and achievements. In: American Society of Pediatric Hematology and Oncology Annual Meeting. N. 648
- Steinherz P (1987) Acute lymphoblastic leukemia of childhood. *Hematol Oncol Clin North Am* 1(4):549–566
- Tamamyán G (2020) Pediatric oncology in the Republic of Armenia: developments in recent years. *Med. Sci Educ*:68–72
- Wikipedia: Armenia (n.d.) <https://en.wikipedia.org/wiki/Armenia>. Accessed 10 March 2021

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