

Greetings dear friends. Allow me to start by thanking the Persian American Society for Health Advancement and the organizers of this wonderful event and especially \_\_\_\_\_ for inviting Mrs. Fereshteh Tavakoli, the executive director of ISCC who has been a volunteer with Mahak since its inception 16 years ago and I to your gathering and giving us the opportunity to introduce Mahak and ISCC to you.

My name is Negin Tafazzoli Mohammadzadeh and I have the great privilege of being able to serve as the current president of ISCC (International Society for Children with Cancer) and work alongside Mrs. Tavakoli.

I will devote the first part of my talk to introducing Mahak and the second part to ISCC and its activities.

Mahak ( ) also known as Society to Support Children Suffering from Cancer was established in Iran in 1991 through the efforts of Mrs. Saideh Ghods. Her inspiration for establishing Mahak was her own darling 2 year old daughter's affliction with this dreaded disease.

The shortcomings she witnessed and the difficulties she experienced during the course of her daughter's treatment, along with seeing first hand the suffering of other parents who were even more desperate than her were very disturbing to her. She was deeply moved by the pain and distress experienced by the disadvantaged during this experience. To quote her words she says: "I felt ashamed of my own restlessness when I saw the agony of the needy."

She saw mothers who would sometimes carry their sick 8 year old child on their shoulders from their village to a main road, then catch a bus or a truck or find any other way to get to the capital, Tehran because they heard that's where they need to go.

Another example was a father who had sold his cow in order to make use of the money to be able to treat his child! These were truly needy people.

Once in Tehran, these families would not know where to go, what to do, or even how involved the treatment of their child would be. They didn't realize how expensive cancer treatments are and that it would take years of follow-up for their child to feel better.

Mrs. Ghods was greatly affected by all of this and out of love wanted to do something so that these people didn't find themselves alone when faced with such agony. She made a pact with God that if her daughter was cured she would do anything she can to help these needy families and their children.

Happily, Mrs. Ghods' daughter completely recovered and today she is a bright young lady pursuing her studies at UC Berkeley. Mrs. Ghods followed up with her pledge and with the help of some wonderful friends and family who came to share her love and compassion for their fellow human beings started Mahak to help indigent children suffering from cancer and their families. As a result, Mahak, Society to Support Children Suffering from Cancer was registered in Iran in 1991 as a non-profit, non-governmental organization and it continues its work 16 years later solely with the help of charitable people. It was built on and for love and it thrives on hope.

At the start of its activities her small group met in a basement room but today with the persistence of Mrs. Ghods and the help of its supporters and volunteers Mahak has grown into a respected, transparent, internationally recognized entity operating a hospital of its own. Mahak is truly a dream that came true.

The primary goal of Mahak is to help reduce the morbidity and mortality of children suffering from cancer and to help indigent children and their families have access to the latest cancer treatments. The organizations other goals include:

- Supporting children with cancer with financial aid for both their medical treatment and non-treatment needs in order to raise their standard of life.
- Training and assistance to children with cancer and their families in order to alleviate physical and emotional suffering.
- Establishing contact and cooperation between the families of children with cancer to help them exchange information to improve the quality of life of the children.
- Increasing public awareness about Cancer and its prevention through mass media.

And

- Creating better means and facilities for looking after children with cancer in hospitals and arranging programs for their entertainment and enjoyment.

Mahak's activities are in line with the 4<sup>th</sup> goal of the United Nations Millennium Development Goals, to help reduce child mortality by two thirds among children under five by the target date of 2015. Since MAHAK's help is directed at those families who are from the poorer section of the society, its activities in helping such families economically and culturally also fulfills the first Millennium Development Goal to help reduce by half the proportion of people living on less than a dollar a day.

Mahak's greatest success since its work began has been the reduction of cancer related fatalities in children, which had always been high in Iran from 80% down to 24% , which is in line with the international standards.

During its first year of establishment Mahak only had one social worker and it helped 5 children by providing part of their treatment expenses. Today Mahak Hospital's chemotherapy unit is equipped with some of the most advanced equipment available, and works with 11 university teaching hospitals in Iran. There is a Mahak office in 3 hospitals in Tehran. Everyday 65 volunteer social workers visit the county hospitals in Tehran, they identify the needy children under the age of 14 diagnosed with cancer, and bring them under Mahak's coverage.

In other words, a miracle happens for these desperate parents. Angels from Mahak try to make sure that children won't die from cancer due to poverty. Moreover, all governmental and university hospitals nationwide that have a hematology department are aware of Mahak's activities and inform the organization of eligible patients so that these children may receive the best medical care available by national standards.

The support Mahak provides these children and their families includes obtaining health insurance for them and providing:

- Diagnostic services
- Hospitalization
- Medications
- Chemotherapy
- Radiation therapy
- Bone Marrow transplantation – as many times as necessary
- Providing prosthetic limbs
- Transportation expenses
- And financial help for living expenses including
- Clothing
- Books
- Educational expenses
- Toys
- And Appropriate meals and snacks
  
- At Mahak these children and their families receive free psychological evaluation and treatment by volunteer psychologists
- Also for those families traveling to Tehran from other provinces free housing is provided during the course of treatment

Today 2000 children who have already been cured still come to Mahak for some of their ancillary services.

Mahak also provides for the children's entertainment:

- During Cancer Week there are puppet shows held daily at 11 Tehran hospitals
- Charshanbeh Souri is celebrated for the kids by taking them to fun places every year
- Books are read at the different hospitals throughout the year by young volunteers
- An annual ceremony is held to break Piggy Banks that have been distributed to children throughout Tehran to make donations and prizes are given to the children
- And finally they have helped equip county hospitals with TVs and appropriate children's videos

In 1998 a four story building was obtained by Mahak in Sattar Khan Street to help house the ill children and their families when they first arrive in Tehran from other cities. There they are provided with all basic necessities and Mahak cars drive them to various hospitals on a daily basis for their treatment needs.

Mahak is the house of hope for children with cancer and their families during their illness, with an ongoing support system afterwards.

It was always Mrs. Ghods' hope to build a clinic or a hospital for Mahak. 10 years ago a piece of land was obtained by Mahak in the Darabad heights of Tehran with the help of one of the friends of Mahak.

Dr. Karbasizadeh and his wife, Ms. Afsaneh Dabiri who was herself afflicted with cancer were the charitable angels who donated the initial sum to help build the hospital.

Dr. Karbasizadeh and his wife were residents of Paris and completely unaware of Mahak's existence. Once Mrs. Dabiri's illness struck they decided to travel to Iran to create a center for patients suffering from cancer. The people they talked to about their decision all introduced and recommended Mahak to them. They went to Mahak and observed the hundreds of people who lovingly and voluntarily devoted their time and resources to this organization so they decided to help pay for the building of their hospital.

Mrs. Dabiri was able to see the half build hospital only once herself during a fundraising ceremony that was being held there. From behind the podium she recited a Rumi poem and prayed for the charitable crowd gathered there never to scatter. With her pale complexion which was a sign of her upcoming departure from this world and in a weak voice she faced the audience and said, "Dear friends I no longer ask God why me. If it wasn't because of my illness I would have never been able to identify with the pain of these children and help make a difference in their lives!" May God rest her soul.

That day a number of generous people made contributions to help equip the hospital. A lady who had lost her young son to cancer helped pay for an amphitheater to be built on the premises and from that day on most of Mahak's fundraising activities are held there.

Mahak's hospital became officially operational in April of 2007. Mahak hospital and rehabilitation complex is located in an 18000 square meter building and has 120 rooms equipped to accommodate patients accompanied by one member of their family. The hospital is one of the most advanced cancer hospitals in the region and since its opening has cared for more than 8000 in and outpatients.

The center houses diagnostic and treatment wards built to the highest standards in developed countries. Within the center there are also further facilities offered such as:

- A clinic
- Chemotherapy laboratory
- Radiotherapy Department
- Physical therapy ward
- Hydrotherapy Department
- Operating Rooms
- MRI and CT-Scan
- Radiology
- ICU
- Library
- Children's Playroom
- A Restaurant
- And an Amphitheatre

The various parts of the complex have been furnished with the help of charitable individuals and as a token of appreciation each section has been named after the donor.

Currently Mahak has 450 volunteers, 210 employees and 32,000 members. The board of directors, the managing director and most of the directors of different departments have been providing their services for free throughout the years.

Around 1000 active young Mahak volunteers also help the organization run smoothly and efficiently. (Some of these volunteers are present here today and I would like to acknowledge them). Everybody who works there adds their magic, and a sense of dedication and love to his or her work.

At the present, Mahak consists of the following departments:

- Social work
- Psychology
- Rehabilitation
- Public Relations
- International Relations
- Fundraising
- Administration
- Finance

At the start of its activities Mahak was solely run by volunteers, but as time went by, the organization's work expanded, and the hospital was completed, a dedicated group of staff was employed. Despite that Mahak is among the most efficiently run charitable organizations in the world. From every dollar donated to Mahak 76 cents goes directly into helping the needy and only 24 cents is spent on administrative costs.

The average cost of treating a cancer stricken child in Iran is \$139/month or \$1670/year.

It the past 16 years Mahak has been able to help 11,458 patients and they have 8417 patients under their coverage at the moment.

Funds for supporting Mahak's activities are provided by the following resources:

- Receiving membership fees
- Receiving cash and non-cash donations
- Distributing donation boxes in Tehran and the provinces
- Holding various charity bazaars
- Holding concerts, art exhibitions
- And Distribution of Piggy Banks to school children which also helps them become familiar with the idea of charity at a young age

All of these events help attract both cash donations and new members to help support MAHAK.

Since the year 2000 Mahak has been a member of The International Confederation of Childhood Cancer Parent Organizations (ICCCPO), a worldwide network of organizations of parents of children with cancer.

It focuses on cooperation and sharing of information and experiences between parent groups around the world so that the treatment and care of children with cancer can be improved.

MAHAK joined the United Nations Socio-Economic Forum, ECOSOC in May of 2001. ECOSOC is the Economic and Social Council of the United Nations. Based on MAHAK's track record, they have gained the special Consultative Status from this organization.

In 2003 Mahak and Cancer Institute of Iran signed a partnership contract for different research programs. This collaboration involves registering demographical studies of children's cancer on the national level as well as cancer data collection.

Last year for the first time, an international conference on pediatric cancer was held in Iran initiated and organized by Mahak at their hospital. Representatives from 25 countries were present at this gathering. As a result of this effort an agreement was signed between Mahak and the Gustav Roussy Institute. The Institute Gustave-Roussy (IGR) is the leading European anti-cancer center and it is located in France. It has 2500 dedicated staff members whose mission is to treat patients suffering from cancer, conduct research and develop new therapies. Mahak is named as one of their affiliates. Its cooperation with this institute focuses on sharing information and research experiences and developing new therapies.

After that conference they also received an admiring letter of commendation from the deputy of the NGO section of the United Nations.

Mahak is also named as one of affiliated research centers of St. Jude Children's Research Hospital in Memphis, Tennessee, one of the world's premier centers for research and treatment of pediatric cancers. Mahak's cooperation with St. Jude focuses on sharing information and research experiences between pediatric hematologists and training of oncologists for improving treatment methods.

Mahak doesn't just help Iranian children with cancer though. Regional conflict and instability in neighboring countries especially in Afghanistan has meant that many people have crossed the border into Iran as refugees. Mahak wished to help Afghan children with cancer, however because the refugee children are not covered by any medical insurance the cost of their treatment was astronomical. Despite this major obstacle, MAHAK took the initiative and tried to help these refugee children even in the early years.

With the increase in the number of refugees MAHAK decided that in order to best serve the needs of these children the help of international bodies was needed. As a result of the Social Work Department's efforts MAHAK succeeded in signing an agreement with UNHCR (the United Nations High Commissioner for Refugees) in order to be able to address the needs of refugee children living in Iran. According to this agreement MAHAK receives a sum from the UNHCR to help refugee children with cancer. Besides receiving financial help from the high commission, the two bodies have been cooperating in social and cultural activities as well. As a result of this cooperation Mahak has been able to provide free treatments to 467 Afghan and Iraqi refugee children thus far.

And finally just a month ago Mahak was presented with the Societe Generale de Surveillance (SGS) NGO benchmarking award for the best managed and most transparent NGO in the Middle East. SGS is the world's leading and oldest inspection, verification and certification company based in Geneva, Switzerland. The certification of this award shows Mahak's extremely high standards in achieving its stated goals and its efficiency and transparency in using funds donated to the organization. This is a further assurance that the money donated to Mahak is truly being spent on the cause.

I really encourage you to visit Mahak if you are going to be in Iran so that you can witness first-hand the love and devotion that has gone into creating this refuge for those in need and the positive energy that keeps it running.

In 2004 during one of her visits to the United States, Mrs. Ghods registered the International Society for Children with Cancer or ISCC in California, keeping in mind the large Iranian population that has immigrated to the U.S. She wanted to make it possible for this group to be able to make tax-deductible donations to help Mahak as well. ISCC is a non-profit organization established in the U.S. to help provide financial assistance for treating indigent children suffering from cancer in third world countries and support their families during the healing process.

It is registered as a charitable organization in the state of California and was granted its 501 (c) (3) tax-exempt status by the Internal Revenue Service in October of 2004.

The mission of ISCC is to help reduce the mortality rate of impoverished children suffering from cancer globally and particularly in developing countries, through financial assistance.

We believe no child suffering from cancer should be left behind and our aim is to help make a difference in the lives of cancer-stricken children, adolescents and their families by giving them access to the highest quality care and service possible regardless of their financial status.

The result of this work has been our ability to help children's cancer organizations in:

- Iran
- Afghanistan
- Bangladesh
- Egypt
- Honduras
- Kenya
- Lebanon
- Turkey

## - And the United States

ISCC is comprised of a unique and dedicated group of volunteers who selflessly donate their time, money, talent, and expertise to aid these destitute children and their families. Our organization is entirely run by volunteers and nearly 100% of your contributions go directly to help those in need.

Thus far we have been able to purchase and send medications to Mahak on a regular basis. There was also a large donation of cancer medication by a charitable physician which we have sent to Iran.

So far we have not had the permission to send money to Mahak directly so a lot of our effort has been focused on familiarizing as many people as possible with Mahak and ISCC's activities through talks and lectures. This has in turn resulted in donations by the kind-hearted people in the audience.

You may be asking yourselves how the collected funds will be forwarded to Mahak. Since Mahak is a well-known NGO in the Middle East with much international recognition and it helps take care of children in immediate need of treatment, our lawyer is working on obtaining a special permission for us to be able to send them this money directly. We are absolutely confident that in the next couple of months this license will be obtained.

Wherever love comes to stay, the impossible becomes possible.

In the meantime an agreement has been signed between Mahak, Gustav Roussy Institute and ISCC so that we may get authorization to purchase the necessary software for the radiotherapy department at Mahak hospital.

I have personally had experiences with many charitable organizations and in my opinion Mahak is the best operated, most modern and best managed NGO in Iran and throughout the world.

On behalf of all the needy cancer- stricken children who so freely enjoy Mahak's benefits I appeal to your kind hearts to find a way to help and support this wonderful organization and its noble cause.

We hope to be able to count on your help by asking all of you to become members of ISCC to aid us in making a difference in the lives of these needy families. I am sure, as current and future physicians you can do a lot to help us. Mrs. Ghods says, "If everyone puts out a light as little as a candle's to light the space around them, pretty soon darkness will disappear throughout the world."

It is up to all of us individually to do what we can to make the world a kinder and better place. After all as Albert Pine so beautifully stated: "What we have done for ourselves alone dies with us. What we have done for others and the world remains and is immortal."

Let's celebrate life and the future with happy children running around with hope for a bright future shining in their eyes.

Thank you so much for your time and attention.

Now I would like to ask Mrs. Tavakoli ISCC's executive director to please join me so that we can answer any questions you might have.