

The 2nd International Congress on the Role of Supportive Bio-Psycho-Socio-Spiritual Services in Multidisciplinary Treatment of Childhood Cancer



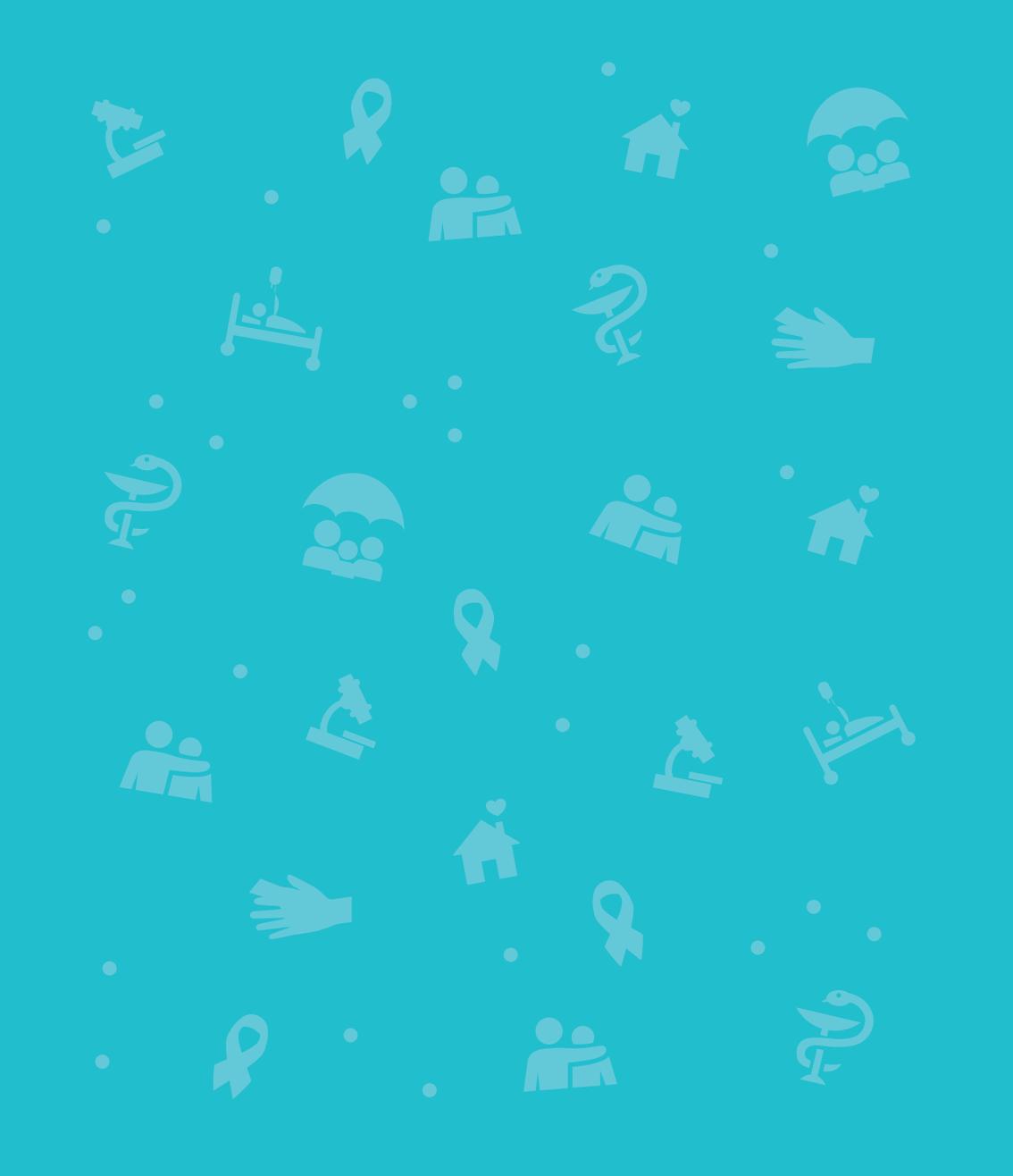
MAHAK
Society to Support Children
Suffering from Cancer

mahak-charity.org

Date: November 22-23, 2017

Venue: MAHAK Amphitheatre





Preface

The Society to Support Children Suffering from Cancer widely known by its acronym, MAHAK, was set up in 1991 as a non-governmental and non-profit organization under the registration number of 6567. From the first day of its activity, MAHAK has always striven to assess cancer-stricken children and their families' needs. Reasoning from this fact, the presence of MAHAK's support services in all public and university hospitals throughout the country with pediatric oncology wards has shorten the interval of cancer diagnosis and receiving support services and minimize the risk of refusing treatment due to insufficient financial means or other difficulties.

From the other point of view, operating on the basis of multidisciplinary approach in cancer treatment, facilitating the challenging days of treatment, and expanding the collaboration between medical team and support services team has led to the expansion of MAHAK's therapeutic and support services day by day through ongoing support of specialists, pundits and supporters. In consideration of the foregoing, MAHAK has held three organized specialized congresses on support services in 2010, 2013, and 2014 with the aim of improving knowledge among specialists and experts, communicating and exchanging experiences among non-governmental organizations with a special consideration in Psychological-Social work interventions and intersectional interaction in social work, psychology and treatment area.

The 2nd International Congress on 'the Role of Supportive Bio-Psycho-Socio-Spiritual Services in Multidisciplinary Treatment Approach' with the presence of national and international pundits will be held at MAHAK in November 2017 in line with assessing the Multidisciplinary Treatment Approach in pediatric cancer.

We hope that organizing such specialized events and exchanging knowledge and experiences will lead to multidisciplinary treatment approach in pediatric cancer throughout the country in order to provide cancer-stricken children with comprehensive treatment and support services and consequently, more effective treatment and life quality improvement.

Support Services at MAHAK



MAHAK support services department including social works, psychology and residential center is one of the most strategic departments directly providing services for cancer-stricken children and their families. The diagnosis of cancer in a child can affect all the family members in many ways; hence, providing them with comprehensive financial, spiritual, welfare and social supports is crucial which is achieved through the productive cooperation between medical and support services teams. Support services department play the role of a coordinator among social work, psychology and residential centers' activities as the communication hub with the children and their families.

This department strives to expand MAHAK's presence across the country and enables the families to solely concentrate on their child's treatment; so children can pass their treatment processes more happily, and change their focus from living or not, to the lives they will lead in the future.

From the very first moment of referring the child with cancer into any of the public or university hospitals with pediatric oncology wards, MAHAK's support services team evaluate the child's family condition from different aspects including financial status, anxieties, psychological status and any other factors affect their life quality. This evaluation is implemented through an interview with the aim of assessing treatment, welfare and support services difficulties for them in order to provide them with better services. Support services department's activities are classified as the following:

- Covering treatment and welfare expenses
- Accommodation services for the cancer-stricken children and their families referring from the other provinces of Iran or other countries at MAHAK's residential centers
- Postoperative care for transplanted patients including isolated place as their residence
- Covering transportation costs
- Organizing national ritual-traditional events
- Cooperating with other universities and charity organizations
- Improving the level of knowledge and expertise of social workers through organizing scientific and educational congresses

Psychologists at MAHAK also strive to manage cancer-stricken children and their families' distress and mental crisis. They stand by the children with cancer and their families from the first moment of diagnosis and offer different services including individual and group counseling, play therapy, art therapy and narrative therapy in order to eliminate the problems which have effects on life quality of them.

Receiving support services from MAHAK will never stop and continue even after treatment completion or loss accordingly MAHAK put its efforts on delivering different support services to the cancer-stricken children and their families about the late effects of cancer, education, marriage, employment and etc.

The 2nd International Congress on the Role of Supportive Bio-Psycho-Socio-Spiritual Services in Multidisciplinary Pediatric Cancer Treatment Approach



The 2nd International Congress on The Role of Supportive Bio-Psycho-Socio-Spiritual Services in Multidisciplinary Pediatric Cancer Treatment Approach will be held on November 22-23, 2017, in Tehran, Iran with the presence of professional social workers, psychologists, psychiatrists, pediatric surgeons, pediatricians, radiologists, researchers, university professors, managers and professionals of NGOs and community based organizations operating nationally and internationally.

During this 2-day congress which will be held with participation of national and international speakers, the audience will have a comprehensive view on the role of psycho-social support services in different stages of diagnosis, during and after the treatment process, remission, and grieving. MAHAK's model of empowering other NGOs, pediatric patients and their families' rights and international trends of offering support services to cancer-stricken children and their families are the other topics which will be discussed.

We hope that through organizing such congress, the latest methods and achievements in multidisciplinary pediatric cancer treatment approach will be introduced in order to providing cancer-stricken children and their families with the best and most proper treatments.

Amir Mahmood Harirchi
Scientific Secretary of the Congress



Let's make a bridge to cross the fears and frustrations: accompanying cancer-stricken children and their families

Families and care givers of children who are recently diagnosed with cancer enter the phase of fear with a series of questions: the final impact of illness, its treatment, the costs, commuting, communication disturbances, blaming, thinking why this has happened to our child at the beginning of his/her life and finally experiencing distress. It is the situation in which they seek a savior to help them and assures them that they are not alone. Several studies have indicated that parents, especially mothers, will return to a normal mental status after accepting the truth and receiving support services within 3-6 months. In

addition, the traumatic and distress symptoms in parents with more vulnerability which may negatively affect children's adaption with their situation especially among adolescents is a significant evidence of the necessity of planning for supportive interventions. the interventions to quick and continuous assessment of the mental health of cancer-stricken children, parents and family, and a multidisciplinary effort to meet these needs that enhance their quality of life and relative relaxation, and take steps towards the shore of hope along the bridge. By supportive interventions parents realize the fact that they are not confronted with sympathies which are sometimes pious, but they face sympathies from professional people, as well as those with whom they are alike. Therefore, they are not alone.

Ali Zadeh Mohammadi
Scientific Secretary of the Congress



The Outstanding Start of Paying Attention to Multidisciplinary Treatment of Children with Cancer

Due to the wide range of its activities and quality of services provided by MAHAK, it is one of the well-known institutions in Iran and the Middle East, and has consistently tried to provide its services within the highest standards.

The collaboration of social workers and psychologists with medical staff at MAHAK hospital for providing comprehensive medical services to cancer-stricken children is one of the standards that has shaped valuable experiences in the field of multidisciplinary treatment and has necessitated sharing experience with other professionals in the field. 'The 2nd International Congress on the Role of Supportive Bio-Psycho-Socio-Spiritual Services in Multidisciplinary Treatment of Childhood Cancer' will be held in November, this year.

At the congress, experts from various fields such as medicine, nursing, psychiatry, psychology, counseling and social work are present in scientific panels to share their expertise in the field of multidisciplinary childhood cancer, and they are lecturing on the concept of "support" from the aspect of multidisciplinary treatment for the first time. Considering the importance of multi-disciplinary treatment, holding this congress can be a good starting point which provides the field of education, experience and exchange of knowledge for the audience.

As MAHAK has already performed outstanding medical and specialized services, I hope that it will be able to transfer its scholarly experiences well into the future, so that we will see the accompaniment of social workers and psychologists with medical staff in hospitals throughout the country.

Dr. Mohammad Faranoosh
Scientific Secretary of the Congress



Collaboration between Social Workers and Psychologists for Improving the Services Provided by Medical Staff

Cancer is one of the most important diseases among children, which, if detected timely and accurately, its rate of recovery will improve. The cancer treatment protocol in Iran is up to date and in accordance with the developed countries. In terms of scientific advances, therapeutic methods, types of medications, studies, research methods, scientific congresses, etc., we are also among the most updated countries in this field. Therefore, there is no significant difference between the results gained from therapeutic methods in Iran and results gained in developed countries. Teamwork and multidisciplinary treatment are the guiding principles of cancer-stricken children's treatment worldwide.

According to the latest scientific findings, a psychologist, a psychiatrist and a social worker's accompaniment with medical staff has a very important role in treatment of childhood cancer, because in these cases, anxious behaviors have increased and due to many conditions, they suffer from social isolation. As a result, the presence of support services experts and the specialists' awareness can increase the hope of recovery in them and their families by reducing the intensity of these factors. It is important to note that children react to family's behaviors due to lack of awareness about issues such as death and recovery, and if the family manage their psychological conditions with psychologists and social workers, the child's treatment occurs more efficiently.

In cases which the child is aware of his or her treatment, they are always faced with social challenges such as the transition from the treatment stage and subsequent recovery. After passing through this stage, children carry a lot of social problems and they pass into adolescence and youth. If the support services' staff be present in the child care phase, these problems also diminish and the child will be immune from high stress because of low social performance in the future.

Another issue is the psychological changes which occur due to cancer treatment. After the treatment, the child experiences a change in mental states such as anxiety, anger, depression, inability to do things, and so on. Here are just psychologists who can improve the conditions of the child through activities such as game therapy, art therapy, music therapy in addition the medical staff help with medical activities. Hospital experience such as MAHAK Hospital has shown that, in many cases, psychologists and social workers with crisis management have provided improvements to the services provided by the health care provider.

On the other hand, the accompaniment of supportive care experts with the medical staff significantly reduces the stress on doctors and nurses. With the presence of psychologists and social workers, the confrontation of doctors with concerns such as the family's financial conditions to provide medicine, awareness of the treatment process, and the reduction of challenges such as patients' death are facilitated.

Now MAHAK is considering sharing experiences with the second international congress on the role of support services in multidisciplinary treatment of childhood cancer, in order to benefit from the knowledge of domestic and international experts in this field to provide multidisciplinary treatment to children with cancer, in the near future, we can safely say that treatment of cancer patients throughout Iran is the same as in the developed countries.

Behnaz Asangari
Executive Secretary of the Congress



Providing Unified and Comprehensive Services to Children with Cancer

MAHAK charity is based on comprehensive support provision for children with cancer and their families, and has always been striving to provide medical and support services to their children in a decent manner based on international standards.

The provision equal service to cancer-stricken children in all cities of Iran has been a wish of the founders of the Institute who has always been striving to integrate these services across the country. The presence of volunteers working to support children with cancer in public and university hospitals with blood and oncology wards throughout the country is among the activities undertaken.

Efforts are now taking another form and MAHAK has put in place its Third Strategic Plan in the next five years to integrate support services across the

country. It is planning to provide all of the support services for children with cancer at MAHAK Hospital, which include 46 supportive packages, in all public and university hospitals throughout the country with blood and an oncology wards based on comprehensive and integrated support and therapeutic standards.

The importance of this issue is to a large extent addressed by the organization at the Second International Congress on Supportive Services, examining the multi-disciplinary childhood cancer treatment, and examining its dimensions in various scientific panels, while improving communication with universities, academic engagement and exchange of experiences with domestic and international professionals.

We believe that by benefiting from the participation of Iranian civil society, there will be a day when all children with cancer will receive equal medical and welfare support services, and in the shadow of these supports, families' only concern will be their children's treatment. Moreover, children will be happier over the process of treatment and their wishes will change from 'living or not' to 'how to live in the future'.

Themes



The main focus of this congress will be “psycho-social support for cancer-stricken children and care givers (family and professionals) in multidisciplinary pediatric cancer treatment approach in the stages of:

- **Diagnosis**
- **During the treatment process**
- **After the treatment process (follow-up)**
- **After remission**
- **Grieving and post-grieving**

Policy Council Members (Alphabetical Order)

Hassan Ashayeri	Neurologist and Psychiatrist
Shiva Dowlatabadi	PhD in Psychology
Dr. Mitra Ghalibafian	Radiation Oncologist
Amir Mahmood Harirchi	General Health Specialist and Social Work Instructor
Shahindokht Kharazmichi	Writer, Researcher and Social Analyst
Farah Lotfi Kashani	Psychosomatic Medicine Specialist
Dr. Azim Mehrvar	Pediatric Hematologist Oncologist
Ali Zadeh Mohammadi	PhD in Clinical Psychology
Tooraj Moradi	Head of Tehran Psychoanalytic Institute
Benson Pau	Member of Board of Directors of Childhood Cancer International (CCI)
Dr. Mohsen Roozrokh	Pediatric Surgeon
Shahram Vaziri	Psycho-Oncologist
Fariba Zarrani	PhD in Psychology of Health

Speakers and Scientific Committee (Alphabetical Order)

Noaman Abdulrahman Ali, Project Manager of Kurdistan Save the Children (KSC) - Iraq
Hamideh Adelian, PhD in Social Work
Habib Agha Bakhshi, Social pathologist
Behnaz Asangari, Manager of Support Services of MAHAK
Prof. Eric Bouffet, Head of International Society of Pediatric Oncology (SIOP) - France
Sediqeh Davoodi, Head of ICU at MAHAK Hospital
Shiva Dowlatabadi, PhD in Psychology
Dr. Mohammad Faranoosh, Hematologist Oncologist
Dr. Mithra Ghalibafian, Radiation Oncologist
Dr. Marziyeh Ghera'at, Social Work Instructor
Tamar Gogatishvili, Founder of Nakvalevi - Georgia
Dr. Nasser Goudarzi, PhD in Clinical and Health Psychology
Mohammad Hatami, Faculty at Kharazmi University
Amir Mahmood Harirchi, General Health Specialist and Social Work Instructor
Dr. Farhad Heydarian, Director of Dr. Sheikh Educational, Research and Therapeutic Center
Saba Kamkar, Manager of Public and International Relations Department at MAHAK
Shahindokht Kharazmi, Writer and Social Analyst
Dr. Farah Lotfi Kashani, Psychosomatic Medicine Specialist
Charles Mbugua, International Federation of Social Worker (IFSW) in United Nations - Kenya

Dr. Azim Mehrvar, Pediatric Hematologist Oncologist
Masoumeh Mousavi, Child and adolescent psychiatrist
Dr. Mohammad Nasiri, director of health-related donors and charities at Ministry of Health and Medical Education
Neda Nedaei, Master of Clinical Psychology
Prof. Issarang Nuchprayoon, Professor at Chulalongkorn University, Bangkok - Thailand
Dr. Amin Rafi'ee Poor, PhD in Psychology of Health
Dr. Mohsen Roozrokh, Pediatric Surgeon
Dr. Alireza Shokrgozar, PhD in Psychology of Health
Shahriar Shahidi, PhD in Health Clinical Psychology
Vahid Sadeghi Firoozabadi, PhD in Health Psychology
Nasser Salehinia, Brain and Cognitive Sciences Researcher
Shirin Sediqnejad, Manager of Provinces' Support Services at MAHAK
Shahram Vaziri, Psycho Oncologist
Prof. Claire Wakefield, Head of Behavioural Sciences Unit at Kids Cancer Center – Australia
Ahmad Yazdanpanah, CEO of the Society to Support Children Suffering from Cancer (Khorasan)
Ali Zadeh Mohammadi, PhD in Clinical Psychology
Fariba Zarrani, PhD in Psychology of Health

Scientific Secretaries

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General Health Specialist and Social Work Instructor
Faculty at University of Social Welfare
and Rehabilitation Sciences

Ali Zadeh Mohammadi

PhD in Clinical Psychology,
Faculty at Shahid Beheshti University

Dr. Mohammad Faranoosh

Pediatric Hematologist-Oncologist, Faculty at
Shahid Beheshti University of Medical Sciences



Panels

1

MAHAK's Approach Towards Support Services Provision Relying on Civil Society Capacity

- The Society to Support Children Suffering from Cancer – Khorasan
- Kurdistan Save the Children (KSC) – Iraq

2

The Role of Support Services in Cancer Diagnosis

- Breaking bad news
- Distress, depression and anxiety management for the patient
- Raising knowledge during diagnosis process based on age, gender and type of disease

3

The Role of Support Services during the Treatment

- Upholding positive outlook and unity of families
- Preserving the quality of life of cancer-stricken children
- Resilience training for caregivers (Families and professionals)

4

The Role of Support Services after Treatment Process (Follow-up) and Remission

- Challenges and difficulties for cancer-stricken children and their families after their treatment process and remission
- The concept and description of support services in this stage
- Building trust for better cooperation between families and health professionals and motivation for continuation of the treatment process
- Cognitive rehabilitation and psychological support for delayed complications of cancer

5

The Role of Support Services during and Post Grieving period

- International trends of grief crisis management
- Methods of maintaining relations with families
- Parents and Siblings' psychological adjustment with loss of a brother/sister



Speeches' Topic

Charles Mbugua

The Role of Support Services in the Stage of Diagnosis

Prof. Eric Bouffet

Achievements and Challenges of utilizing Multidisciplinary Treatment of Childhood Cancer

Shiva Dowlat Abadi

Pediatric Patients' right

Nasser Salehinia

Post Trauma Stress Syndrome

Prof. Claire Wakefield

the Role of Support Services during Treatment Process

Tamar Gogatishvili

Survivorship

Prof. Issarang Nuchprayoon

Palliative Care at Home for Cancer-stricken children

Mission Statement 2017-2021



MAHAK is a philanthropy established with the charitable and altruistic goal of serving humanity by combatting pediatric cancer nationally and internationally through medical care, research and support services. MAHAK is a non-profit, non-political, and non-governmental charity, dependent exclusively on public support provided in the form of funds, as well as in-kind, goods, services, and technical expertise.

Offering comprehensive services to children with cancer and their families, providing the most advanced and effective treatment services while observing the International Charter of Patients' Rights, employing up-to-date scientific advances and establishing a new research center in order to contribute to identifying the causes of childhood cancer, and its preferred methods of diagnosis, prevention, and treatment comprise the mission of this organization. In contributing to the reduction of the pediatric cancer rate in Iran, MAHAK has adopted a novel approach by investing in raising awareness, and in prevention education. With the objective of optimally utilizing human resource

capabilities, volunteers and employees work in close cooperation to make sure humanitarian objectives are met to the highest standards. Accessing the most recent technologies enables us to further develop key capabilities.

By addressing pediatric cancer in this manner, MAHAK espouses the ideal of helping fellow human beings. Transparency, appreciation, and accountability are MAHAK's most valued principles.

MAHAK, is a multi-disciplinary organization with one of the largest specialized hospitals in the Middle East and as a result of its commitments and transparency in giving comprehensive services under one roof according to international best practices, is the most trusted organization for individual and institutional benefactors who believe in the optimal utilization of scarce resources as measured by effectiveness and efficiency indices.

Vision Statement 2017-2021



MAHAK believes that parents should have no other concern than their children's recovery and also believes that with the parents present, the children can pass the treatment processes more happily, with more hope and that consequently both children and parents can change their focus from living or not, to the lives they will lead in the future.

MAHAK ensures that every child with cancer and their families receive comprehensive and integrated services across the country and provides them with up-to-date treatment services in accordance with national and International standards. By raising awareness and education, effective diagnosis occurs in the early stages and support is provided from the very first moment a

diagnosis is rendered. MAHAK strives to provide the public with the latest cancer-related information, news, necessary resources and recommendations, and by expanding its cooperation with national and international research and treatment centers, MAHAK employs the most effective methods of cancer treatment, consequently decreasing the rate of pediatric cancer.

MAHAK is known as a charity organization that serves as a model for reliability, as well as for the implementation and evaluation of programs for national and international organizations alike. By all standards, MAHAK finds its place as a top-ranked organization among NGOs, not only overall, but also in every field of its numerous activities.



MAHAK International Standpoints

- Ranked as the 4th Ngo in the world by Société Generale de Surveillance (SGS) NGO benchmarking among 299 organizations in 2016
- Gained consultative status with the United Nations Economic and Social Council (ECOSOC) in 2001
- Recipient of the Gold Award from the International Project Management Association (IPMA) in 2014
- Recipient of the Quality Silver Trophy from GIC International Institute in 2011 and 2017
- Recipient of the Silver Prize for Green Project Management (GPM) in 2014
- Membership in Union for International Cancer Control (UICC) since 2008
- Membership in Childhood Cancer International (CCI) since 2000
- Membership in CCI's Regional Committee since 2012
- Collaboration with United Nations High Commissioner for Refugees (UNHCR) since 2007
- Membership in United Nations Global Compact since 2016
- Membership in the International Chamber of Commerce (ICC) since 2014
- Membership in the Society of Hematologic Oncology (SOHO) since 2015
- Collaboration with LÖSEV the Foundation for Children with Leukemia in turkey since 2013
- Educational Collaboration with Relief International since 2016
- Collaboration with Kurdistan Save the Children (KSC)
- Collaboration with Saint Jude Research Center since 2007
- Collaboration with Gustav-Roussy Institute (IGR) since 2007
- Membership in International Network for Cancer Treatment and Research (ICTR) since 2009
- Membership in MedicRes Institute since 2011
- Membership in the following International Associations for Blood and Marrow Transplantation since 2015:
 1. European Group for Blood and Marrow Transplantation (EBMT)
 2. American Society for Blood and Marrow Transplantation (ASBMT)
 3. Membership in Asia-Pacific Blood and Marrow Transplantation Group (APBMT)
 4. Eastern Mediterranean Blood and Marrow transplantation (EMBMT)

Scientific Supporters



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