



The Margaret Hackett Family Center and the
Margaret Hackett Family Program
At the University of Chicago Medicine

Program Update, March 2023

The Margaret Hackett Family Center (MHFC) is a private philanthropic organization and their mission is to help you overcome the challenges of living with CNS congenital anomalies through support, innovative treatments, research and compassion.

The MHFC provides philanthropic support for the Margaret Hackett Family Program (MHFP) at UChicago Medicine. The MHFP builds on UChicago Medicine's extensive expertise in treating CNS anomalies.

The Margaret Hackett Family Program (MHFP) in CNS Congenital Anomalies at the University of Chicago is committed to enhancing the treatment, care, and outcomes of patients with central nervous system anomalies.

Our shared vision is to help patients and families understand and better address the challenges of living with CNS anomalies. This includes understanding the diagnosis, and identifying optimal treatment to improve the overall quality of life for the patients and families dealing with these life-altering diseases.

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mhfamilycenter.org

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The team at UChicago Medicine is approaching this challenge through focused activities in the following areas:

- **Pillar 1:** Provide a warm and compassionate destination for the children and adults seeking answers and needed treatment.
- **Pillar 2:** Establish and lead a network of medical experts committed to the care of children and adults seeking answers and needed treatment.
- **Pillar 3:** Create and maintain a database of knowledge and resources for those navigating and treating these conditions.
- **Pillar 4:** Advance innovative research initiatives exploring the circumstances and developmental mechanisms, impact and options for improved care and options.

Highlights/Progress of the Margaret Hackett Family Program over the past year

- 2022 was a pivotal year as Dr. Bakhtiar Yamini (MD) assumed the role of Program Director from Dr. David Frim (MD, PhD). Dr. Yamini has been actively involved in the Program since mid 2021. Dr. Yamini is fully aligned with the Program mission and focus and is/has been a strong and committed advocate of our work. Importantly, he has been instrumental in refocusing and aligning the program work and budgets to ensure consistency with the Program's Purpose and Mission.
- The Program's outreach to the Chicago community has been significantly enhanced thru the partnership of UChicago Medicine, Advocate Health and NorthShore Hospitals, known as the Chicagoland Children's Alliance. The team has and will continue to conduct informational outreach to neurosurgeons, doctors, medical professionals and patients/families through these partnerships. Attached you will find a flyer outlining one of the scheduled forums to take place in April.
- In addition to Dr Yamini, the MHFP Professional Consortium currently includes the following medical professionals: Dr. Moise Danielpour (MD), Cedars Sinai Hospital; Dr. Lissa Baird (MD), Boston Children's Hospital; Dr. Tina Sayama (MD, MPH), Oregon Health and Science University; and Dr.

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David Bauer (MD, MPH), Texas Children's Hospital. Aside from providing input and oversight of ongoing Program initiatives, each of these doctors are engaged in research project(s) consistent with our mission and with the intention of publishing the results, thus providing the medical community with valuable insights/information. These projects are partially funded by the MHFP.

- The Program is also underwriting a research scientist at UChicago Medicine, Dr. Seif Gholampour (PhD). Dr. Gholampour (PhD) has a number of research initiatives in process, which could have significant implications for patients dealing with a range of challenges. He has already published papers citing the MHFP as an underwriter of his work and several other papers are in process.
- Aside from the research noted above, this past year the program initiated a research grant program open to UChicago Medicine students and staff to fund approved project(s) that align with our mission. The first of these grants will be awarded during the upcoming 5th Annual Margaret Hackett Family Program Symposium on May 12th.
- The Program database templates have undergone a significant rework to be more targeted/responsive/accessible to potential research and reference work by medical and research professionals.
- The team has initiated a quarterly review process with the Board to ensure accountability and Plan follow through of the team's activities/work.
- The Fifth Annual Margaret Hackett Family Program Symposium: Modern Perspectives on Congenital Skeletal Disorders is scheduled for May 12, 2023. After two years of virtual Symposiums, we are thrilled to be offering this program live...and virtually for those that can't attend. The Program is CME Accredited and fully funded by MHFP.
- One final point. As mentioned, Dr. Yamini has transitioned into the role of Program Director and is enthusiastically engaged with our mission and, as evidenced by the progress detailed above, he is making a difference. However, I would be remiss if I didn't acknowledge how much the MHFP

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owes to Dr David Frim, the original visionary of the Margaret Hackett Family Program. It was his foresight and vision that framed the Program from the very start and it remains the vision of the program today. From all of us **Thank You** Dr. Frim for your undying advocacy of all patients who face these challenges that require incredible efforts, risk and knowledge not found in textbooks... not to mention, an undying commitment to success!! And **Thank You** for your advocacy and commitment to Margaret over all these years!! She and we will never forget!

To all of our supporters...Thank You. You are the ones that make this work possible!!

Cheers,

The Hacketts, the MHFP Board of Directors and the UChicago Medicine Team

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