

## Mental Health Implementation Grants—Inaugural Round—2022

In 2022 we began a program to assist JM clinical providers in integrating more mental health care into their practices and clinics. We made three grants of \$5,000 each.

Here are the grantees:

### #1 Sick Kids Hospital of Toronto

**Project Investigators/Leaders:** Dr. Andrea Knight; Ingrid Goh, Ph.D. (Senior Research Associate, QI consultant)

**Project Title & Description:** *Implementing and Evaluating the Impact of Mental Health Screening Program in JM clinic*

#### Project Aims:

- 1) To implement mental health screening in the JM clinic and increase the rate of screening and follow up of patients with JM (aged 5 –18 years) from 0% to 50% within one year, from November 2022 to November 2023.
- 2) To ensure that within the above 1year period, 100% of patients with positive screens are assessed and followed up by a social worker who is integrated into the JM clinic.

#### Anticipated Project Outcomes/Deliverables:

1. Establishment of a formalized mental health screening process tailored to JM clinic
2. Improved and standardized healthcare system processes that are equitable to all JM patients
3. Develop healthcare provider training materials and resources for the mental health care of JM patients
4. Trained clinicians to provide specialized and comprehensive care for better JM health outcomes

#### Dissemination of End Product:

- The program framework will be shared with other pediatric rheumatologists and institutions to improve equitable access to mental health screening and care.
- We will disseminate our findings using a variety of mechanisms, including meetings, conferences, publications, and websites. Materials and educational resources developed as a part of this project will be shared with other institutions wishing to implement a mental health screening program; we will create a document outlining logistical considerations (e.g., human resources, infrastructure, training, program evaluation, referral pathways).

#### Future Vision and Next Steps:

- Our vision is standardized, equitable, and accessible mental health screening for children with JM and the availability of resources to support the mental health of all family members. Early identification of individuals who require mental health support will enable timely access to services, thereby improving their long term outcomes.

- Our next steps include expanding mental health resources to include the entire family unit, as previous studies suggest that siblings of children with chronic conditions are also affected [3,4]. We will seek additional funding to support this endeavor, including, but not limited to, Patient Centered Outcomes Research Institute, Canadian Institutes for Health Research, and Bell Let's Talk Community Fund.

## #2 University of Minnesota

**Project Investigators/Leaders:** Dr. Colleen Correll; Kavita Desai Dakoiji, PhD

**Project Title & Description:** *Removing Barriers: Using Digital Learning to Bring Mental Health Education to Children and Adolescents with Juvenile Myositis and Systemic Lupus Erythematosus*

### Project Aims:

We aim to bring mental health resources directly to patients with JM and SLE with a two-pronged approach:

#### 1) Engage digital learning:

Create mental health wellness and resilience-building videos (5-10 minutes each) specific for JM and SLE that are engaging and have associated activity sheets (as developmentally appropriate).

Video 1: "Introduction to the illness" (brief description of JM and SLE)

Video 2: "Resetting after the diagnostic process: validating the often roundabout and exhausting diagnostic processes, and healing the hurt/scars from the process."

Video 3: "Befriending your illness: coming to terms with your own body."

Video 4: "Stress and our bodies: understanding how our thoughts and actions can cause further harm or healing."

Video 5: "Daily resiliency building: focus on living, creating positive memories, and trusting your medical team."

#### 2) Interactive workbooks to reinforce skills learned.

We will pair the videos with activity books to reinforce learning.

To do this, we will partner with Kavita Desai Dakoiji, PhD (Dr. Kavita), to create short, educational videos about JM, SLE, chronic stress, and building resilience (see below) and pair the videos with age-appropriate activity books.

**Impact and Expected Outcomes:** We expect that when we bring this tailored content to our patients, we will teach them tools, including managing stress and building resiliency. We also think that it will decrease the stigma around mental health and will allow patients to more easily discuss their mental health concerns with their providers. Psychoeducational approaches such as these are highly effective, and they are a unique approach to bringing mental health into medical care without requiring one-on-one therapy. If successful, we will plan to expand these videos in content, including adding other rheumatic diseases and other psychoeducational topics.

Method of Dissemination: We plan to host these videos on [peaceoutpain.com](http://peaceoutpain.com), with links directly to Cure JM's website. Cure JM will be recognized as the sponsoring organization. The videos will be open-access (or password-protected, per Cure JM Foundation's preference). Corresponding activity sheets will be available to download as PDFs and can be printed if desired. At the University of Minnesota, our medical team plan to share the videos on a tablet and activity sheets with patients while they are in the waiting room at their routine clinic appointment or during infusion, recognizing that some patients face barriers to accessing this content at home.

### #3 Seattle Children's Hospital

**Project Investigators/Leaders:** Dr. Aviya Lanis (2nd yr. Fellow);

**Project Title & Description:** *Narrative Medicine as a Mechanism to Improve Mental Well-being in Patients with Juvenile Myositis*

#### Project Aims:

1. This project will offer an opportunity for patients with JM to participate in a narrative medicine intervention with an effort to improve mental health outcomes.
2. This project will be conducted at Seattle Children's Hospital (SCH) Juvenile Myositis Center of Excellence (COE), using a Narrative Medicine curriculum as a mental health intervention for patients with JM. Ultimately, this project will aim to provide training for the implementation of a narrative medicine curriculum that can be used at other institutions, providing an alternative approach to improving mental health among patients with JM.

#### Project Approach:

1. To complete these aims, participants ages 6 to 21 with myositis will be asked to participate in bi-monthly video-based 1-hour narrative medicine sessions over the course of 3 months (6 sessions total).
2. Sessions will include 4-6 patients per session, with a trained physician researcher (AL—Principal Investigator) and social worker as facilitators. Age-appropriate interventions, including poetry, photography, art, and music, will be used to engage participants and prompt discussions around unique medical experiences.
3. Participants will complete validated patient-reported outcomes and questionnaires about disease activity, anxiety, depression, Covid-related stress, and children's attitude towards their illness both before and after completion of the narrative medicine intervention.
4. Participants will be asked for their perspectives on intervention so as to incorporate participant feedback in future sessions.

### **Project Dissemination & Impact:**

Following completion of the narrative medicine intervention through the SCH JM COE, the principal investigator will advertise the use of the curriculum through CARRA JDM and Narrative Medicine Workgroups. Clinicians will be polled for educational impact of narrative medicine training to understand the perceived utility of this narrative medicine curriculum. The goal is to establish a multi-center cohort of trained narrative medicine individuals who can implement the narrative medicine curriculum at their own institutions, thus maximizing the impact for patients with JM.