Workgroup Sessions and Leaders

Cross-Cutting
Mental Health
Tuesday, April 28 - 8:45am - 11:45am
We will be developing plans for implementation studies regarding screening pathways for mental health symptoms in the pediatric rheumatology clinic. This work will draw from workgroup consensus statements developed broadly for pediatric rheumatology patients by a multiple-stakeholders taskforce (patient, caregiver, mental health provider, rheumatologist) on the assessment and treatment of mental health conditions in pediatric rheumatology practice. We highly encourage patient and family, as well as behavioral health provider participation.
Natosha Cunningham natosha@msu.edu
Andrea Knight andrea.knight@sickkids.ca
Tamar Rubinstein trubinst@montefiore.org

Reproductive Health
Tuesday, April 28 - 1:30pm - 3:00pm
Rheumatic diseases and their medications are concerns of patients, parents and providers with little research done in this arena. Our CARRA 2020 session will have a guest speaker with a robust history of research and grant acquirement in the field of reproductive health and rheumatic diseases in adults to discuss how their research path can be a foundation and inspiration for this type of research and education for pediatric patients, families and those providing rheumatology care.
Cuoghi Edens reprorhueum@gmail.com
Veronica Mruk veronica.mruk@nationwidechildrens.org

Implementation Science
Tuesday, April 28 - 5:30pm - 7:00pm
The newly formed Implementation Science Workgroup was launched at the 2019 CARRA meeting. Our goal is to facilitate implementation of CARRA research findings and to advance the CARRA Consensus Treatment Plan (CTP) program. During CARRA 2020, the workgroup will have a review of Implementation Science 101, work on a CTP survey to assess knowledge, perspectives and barriers of CTP program and have break out sessions.
Cagri Yildirim Toruner cagri.toruner@nationwidechildrens.org
Emily von Scheven evonsche@ucsf.edu
Veronica Mruk veronica.mruk@nationwidechildrens.org
Rajdeep Pooni rpooni@stanford.edu
Rosemary Peterson rpeters1615@gmail.com
Transition
Wednesday, April 29 - 8:45am - 11:45am
The first half of the session will be a group exercise to develop the research priorities related to transition. Parents, patients, and foundation representatives are especially encouraged to attend. The second half will be an improvement learning session for the Transition Learning Collaborative focused on implementation of transition policy dissemination across pediatric rheumatology practices.
Erica Lawson erica.lawson@ucsf.edu
Joyce Chang changj2@email.chop.edu
Hana Conlon hc2633@cumc.columbia.edu

Informatics
Wednesday, April 29 - 10:15am - 11:45am
At this time, there is no specific workgroup that utilizes health information technology though it is a discipline that may be applied to multiple disease states and research topics of interest including transition, reproductive health, mental health and other stakeholders in pediatric rheumatologic care. This interest group session will discuss the topic of informatics in healthcare and seeks to further discuss its role, and potential as a workgroup, in CARRA.
Rajdeep Pooni rpooni@stanford.edu

Early Investigators
Intro to CARRA, Engagement, and Panel
Monday, April 27 - 8:00am - 10:00am
The goal of the Early Investigator Introduction to CARRA session is to “demystify” CARRA for early investigators, while demonstrating how EIs can use CARRA to advance their careers. We will learn about the structure of CARRA and opportunities for EI engagement, and hear from a panel of EIs who have leveraged CARRA to pursue their research interests and achieve their goals.
Erica Lawson erica.lawson@ucsf.edu
Kaveh Ardalan kardalan@luriechildrens.org

Aims Review
Monday, April 27 - 10:00am - 12:00pm
The goal of the Early Investigator Specific Aims Review is to provide CARRA Early Investigators (including senior fellows) who are currently developing research grant proposals the opportunity to receive feedback from senior CARRA researchers, improving the odds of a successful grant submission. Participants will break into small groups of approximately 4 EIs and 2 senior CARRA researchers to discuss the specific aims page of each EI participant (~25 minutes per page). Please note that in order to participate in the session, each EI must submit a draft specific aims page for their grant proposal, as well as target funding mechanism(s), no later than 4/6/20.
Erica Lawson erica.lawson@ucsf.edu
Kaveh Ardalan kardalan@luriechildrens.org

Preparing for Promotion
Monday, April 27 - 10:00am - 12:00pm
The Early Investigator Preparing for Promotion Workshop will begin with an overview of the promotions process and criteria at most institutions. Afterwards, participants will break out into groups based on their area of academic interest to discuss important steps and strategies to prepare for promotion. Finally, an optional breakout session for CV review will provide EIs the opportunity to receive specific feedback on their CV.
Erica Lawson erica.lawson@ucsf.edu
Kaveh Ardalan kardalan@luriechildrens.org
Leadership Training
Monday, April 27 - 1:00pm - 2:00pm
Research is a team sport! The goal of the Early Investigator Leadership Training session is to prepare EIs to lead and participate in collaborative research. EIs will engage in a combination of didactic training and small-group work.
Erica Lawson  erica.lawson@ucsf.edu
Kaveh Ardalan  kardalan@luriechildrens.org

Medical Education Research
Tuesday, April 28 - 8:45am - 11:45am
During our session, we have two goals: 1) workshopping attendees' rheumatology medical education research projects on which they'd like feedback or are looking for collaborators; 2) Further development of the national fellows' Pediatric Rheumatology Objective Structured Clinical Exam, which will be held in early fall 2020
Jay Mehta  mehtaj@email.chop.edu
Megan Curran  mcurran@luriechildrens.org
Kristen Hayward  kristen.haward@seattlechildrens.org

Fellows
Fellows Meeting
Sunday, April 26 - 5:15pm - 7:15pm and Monday, April 27 - 8:00am - 12:00pm
Come and join other fellows for sessions dedicated to the job search and career development. Additionally, we will have sessions focusing on how CARRA can be a part of your career regardless of your career track, and tips for developing your own projects both as a fellow and as an attending.
Ashley Blaske  ashley.l.blaske@vumc.org
Laura Cannon  laura.cannon@duke.edu

Juvenile Dermatomyositis
JDM/SLE Dermatology
Tuesday, April 28 - 8:45 am - 11:45 am
The intent of this work group is to identify unmet needs in pediatric patients with cutaneous manifestations of lupus or dermatomyositis. The objectives for the meeting are to:
1) share data on ongoing/completed projects (DLE, projects in JDM), 2) review bottlenecks, brainstorm solutions, and assist with execution of projects launched at the 2019 CARRA Meeting (with a focus on supporting Early Investigators), and 3) identify new research questions surrounding gaps in clinical practice/knowledge, with selection of key stakeholders and interested investigators from the group.
Lisa Arkin  larkin@dermatology.wisc.edu
Kaveh Ardalan  kardalan@luriechildrens.org

Quality Measures in JDM
Tuesday, April 28 - 8:45 am - 11:45 am
The mission of this work group is to develop a standardized approach to measuring and improving the quality of care for patients with JDM. Activities and objectives of the meeting will include discussion of ongoing projects related to quality measures and patient reported outcomes and further work on the development of a set quality measures through Delphi methodology.
Heather Tory  htory@connecticutchildrens.org
Biologics in JDM
Tuesday, April 28 - 1:30 pm - 3:00 pm
The biologics in JDM CTP committee will review the results of the survey developed at the last CARRA meeting. This data will be used to finalize the CTP.
Stacey Tarvin starvin@iu.edu
Charles Spencer spencercharlesh1@gmail.com

Calciosis in JDM
Tuesday, April 28 - 5:30 pm - 7:00 pm
The aim of our group is to improve the understanding, treatment and outcome for JDM-associated calciosis. Our current project is a large, focused case series that is in the data collection phase. Writing assignments, sub-projects and authorship to be discussed.
Amir Orandi orandi.amir@mayo.edu

Translational Medicine in Juvenile Myositis
Wednesday, April 29 - 8:45 am - 11:45 am
The newly formed Implementation Science Workgroup was launched at the 2019 CARRA meeting. Our goal is to facilitate implementation of CARRA research findings and to advance the CARRA Consensus Treatment Plan (CTP) program. During CARRA 2020, the workgroup will have a review of Implementation Science 101, work on a CTP survey to assess knowledge, perspectives and barriers of CTP program and have break out sessions.
Jessica Turnier turnierj@med.umich.edu
Jessica Neely jessica.neely@ucsf.edu

Juvenile Idiopathic Arthritis
Ultrasound Meeting #1
Tuesday, April 28 - 8:45am - 11:45am
Ankle Protocol – scoring exercise for the Tibiotalar joint (TTJ)
• Review of current proposed ankle protocol and scoring system for evaluation of the TTJ
• Scoring exercise of TTJ with pre-generated images with ankle arthritis
• Review results of the scoring exercise, discuss and modify scoring system as necessary
Tracy Ting tracy.ting@cchmc.org
Johannes Roth jroth@cheo.on.ca
Ed Oberle edward.oberle@nationwidechildrens.org
Deirdre De Ranieri dderanieri@luriechildrens.org
Hulya Bukulmez hxb38@case.edu
Patricia Vega-Fernandez patricia.vegafernandez@cchmc.org

TMJ Interest Group
Tuesday, April 28 - 8:45am - 10:15am
JIA associated TMJ arthritis affects the majority of our patients. The TMJ group aims to improve recognition, early diagnosis, treatment and better outcomes for patients affected with TMJ arthritis. The group works closely with the TMJaw group.
Marinka Twilt marinka.twilt@ahs.ca
Melissa Lerman lermanm@email.chop.edu
Ultrasound Meeting #2a
Tuesday, April 28 - 1:30pm - 3:00pm
Ankle protocol - Scoring System for the Subtalar joint (STJ)
• Review of current proposed ankle protocol and scoring system for evaluation of the STJ
• Scoring exercise of STJ with pre-generated images with STJ arthritis
• Review results of the scoring exercise, discuss and modify scoring system as necessary
Tracy Ting  tracy.ting@cchmc.org
Johannes Roth  jroth@cheo.on.ca
Ed Oberle  edward.oberle@nationwidechildrens.org
Deirdre De Ranieri  dderanieri@luriechildrens.org
Hulya Bukulmez  hxb38@case.edu
Patricia Vega-Fernandez  patricia.vegafernandez@cchmc.org

Uveitis
Tuesday, April 28 - 1:30pm - 3:00pm
We will be reviewing progress from current projects and discussing updates from the uveitis world at large. We plan active discussion of two new projects (registry of difficult patients and recapture of disease flares), and welcome all to join.
Mindy Lo  mindy.lo@childrens.harvard.edu
Ashley Cooper  amcooper@cmh.edu

Inactive Disease
Tuesday, April 28 - 5:30pm - 7:00pm
For the first hour, we will discuss the development and testing of a shared decision making tool for children with JIA in remission on medications. In the last half hour, those who are interested are invited to discuss plans for testing biomarkers of biologic remission on methotrexate.
Daniel Horton  daniel.horton@rutgers.edu

Ultrasound Meeting #2b (continuation from #2a)
Tuesday, April 28 - 5:30pm - 7:00pm
Ankle protocol - Scoring System for the Subtalar joint (STJ)
• Review of current proposed ankle protocol and scoring system for evaluation of the STJ
• Scoring exercise of STJ with pre-generated images with STJ arthritis
• Review results of the scoring exercise, discuss and modify scoring system as necessary
Tracy Ting  tracy.ting@cchmc.org
Johannes Roth  jroth@cheo.on.ca
Ed Oberle  edward.oberle@nationwidechildrens.org
Deirdre De Ranieri  dderanieri@luriechildrens.org
Hulya Bukulmez  hxb38@case.edu
Patricia Vega-Fernandez  patricia.vegafernandez@cchmc.org
Ultrasound Meeting #3
Wednesday, April 29 - 8:45am - 11:45am

Ankle protocol - Scoring System for tendons and the Talonavicular joint (TNJ)
- Review of current proposed ankle protocol and scoring system for evaluation of the TNJ and tendon compartment
- Scoring exercise of TNJ with pre-generated images with TNJ arthritis and tendon pathology
- Review results of the scoring exercise, discuss and modify scoring system as necessary

Finalization and Future direction
Tracy Ting  tracy.ting@cchmc.org
Johannes Roth  jroth@cheo.on.ca
Ed Oberle  edward.oberle@nationwidechildrens.org
Deirdre De Ranieri  dderanieri@luriechildrens.org
Hulya Bukulmez  hxb38@case.edu
Patricia Vega-Fernandez  patricia.vegafernandez@cchmc.org

Systemic Juvenile Idiopathic Arthritis
Wednesday, April 29 - 8:45am - 10:15am

We will be discussing multiple new and ongoing studies evaluating children with sJIA. These include studies about interstitial lung disease, distinction between disease flare and infection, and predictors of inactive disease.
Rebecca Trachtman  rebecca.trachtman@mssm.edu

Pain
Introductions and Research Updates
Tuesday, April 28 - 8:45am - 9:45am
Melissa Tesher, et al study on evaluating the proportion of children with JIA who meet criteria for co-morbid JFM, using the Pain Symptom Assessment Test (PSAT).
Amy Gaultney, et al study describing the prevalence of widespread pain in patients with pSLE and JDM and exploring the relationship between the presence of widespread pain and functional disability (as measured by the CHAQ and PROMIS Pain Interference scale) in these patients.
Melissa Tesher  mtesher@peds.bsd.uchicago.edu
Amy Gaultney  agaultney@mednet.ucla.edu
Susmita Kashikar-Zuck  susmita.kashikar-zuck@cchmc.org

Planning Research Priorities
Tuesday, April 28 - 9:45am - 11:45am
Small group format brainstorming session.
Susmita Kashikar-Zuck  susmita.kashikar-zuck@cchmc.org
Jennifer Weiss  jennifer.weiss@hackensackmeridian.org
Planning for Multi-site PSAT Validation Study
Tuesday, April 28 - 1:30pm - 3:00pm
The Pain Symptom Assessment Test (PSAT) is a modified version of the 2010 ACR fibromyalgia criteria and has demonstrated good specificity and sensitivity for diagnosis of juvenile primary fibromyalgia syndrome in adolescents. This planning session will lay the framework for a multi-site validation study of the PSAT in JIA patients.
Susmita Kashikar-Zuck  susmita.kashikar-zuck@cchmc.org
Jennifer Weiss  jennifer.weiss@hackensackmeridian.org

Pain in Pediatric Rheumatology/Update on JIA Option Map
Tuesday, April 28 - 5:30pm - 7:00pm
Karin Toupin-April  ktoupin@cheo.on.ca

Update from Research Priorities
Wednesday, April 29 - 8:45am - 9:45am
Sharing results of brainstorming session on research priorities.
Susmita Kashikar-Zuck  susmita.kashikar-zuck@cchmc.org
Jennifer Weiss  jennifer.weiss@hackensackmeridian.org

Setting the Agenda/Task List for 2020-2021
Wednesday, April 29 - 9:45am - 10:15am
Susmita Kashikar-Zuck  susmita.kashikar-zuck@cchmc.org
Jennifer Weiss  jennifer.weiss@hackensackmeridian.org

Research Coordinator Network
Research Coordinator Meeting
Monday, April 27 - 8:00am - 12:00pm
The Research Coordinator Meeting is open to all CARRA Research Coordinators and collaborators. This meeting is designed to encourage networking among CARRA research coordinators and to foster the coordinator community within CARRA. This session will be focused on how to continue to improve enrollment in the CARRA Registry, biospecimen collection and CARRA substudies through study overviews, a panel discussion, and skill building workshops to increase efficiency.
Mary Ellen Riordan  maryellen.riordan@hackensackmeridian.org
Chelsey Smith  cnsmith1@cmh.edu

Systemic Lupus Erythematosus
JDM/SLE Dermatology
Tuesday, April 28 - 8:45am - 11:45am
The intent of this work group is to identify unmet needs in pediatric patients with cutaneous manifestations of lupus or dermatomyositis. The objectives for the meeting are to:
1) share data on ongoing/completed projects (DLE, projects in JDM), 2) review bottlenecks, brainstorm solutions, and assist with execution of projects launched at the 2019 CARRA Meeting (with a focus on supporting Early Investigators), and 3) identify new research questions surrounding gaps in clinical practice/knowledge, with selection of key stakeholders and interested investigators from the group.
Lisa Arkin  larkin@dermatology.wisc.edu
Kaveh Ardalan  kardalan@luriechildrens.org
Antiphospholipid Syndrome/Neuropsychiatric Lupus/General
Tuesday, April 28 - 1:30pm - 3:00pm
This session will focus on development of projects for the antiphospholipid syndrome workgroup, as well as a new workgroup for neuropsychiatric lupus.
Elizabeth Sloan  elizabethsloan@gmail.com
Andrea Knight  andrea.knight@sickkids.ca

Lupus Nephritis
Wednesday, April 29 - 8:45am - 11:45am
We will open our session with a didactic session on novel therapeutics for lupus nephritis. Workgroup members with current projects will provide updates to the group. In the remaining time, workgroup members will divide into subgroups to advance current projects or begin to develop new topics of interest.
Laura Lewandowski  laura.lewandowski@nih.gov
Scott Wenderfer  wenderfe@bcm.edu

Scleroderma, Vasculitis, Auto-Inflammatory and Rare Diseases
ANCA-Associated Vasculitis
Tuesday, April 28 - 8:45am - 11:45am
1. pVAS/pVDI education and case-based scoring exercises for measurement of disease activity and damage in AAV for education and research purposes, in preparation for CTP study.  2. Review details of prospective AAV CTP study and recruit more participants. 3. Subgroup to work on a dedicated website for pediatric AAV, collaborating with the Vasculitis Foundation
David Cabral  dcabral@cw.bc.ca
Linda Wagner-Weiner  lww@uchicago.edu
Eric Yen  eyen911@gmail.com
Vidya Sivaraman  vidya.sivaraman@nationwidechildrens.org
Kathleen O'Neil  kmoneil@iu.edu

CNO/CRMO
Tuesday, April 28 - 8:45am - 11:45am
We plan to review the currently ongoing projects including the development of CNO/CRMO classification criteria, observational patient registry (CHOIR), collaboration with CRMO Foundation and core domain set development based on OMERACT methodology. We will discuss domain items in small groups after literature review presentation.
Eveline Wu  eveline.wu@unc.edu
Fatma Dedeoglu  fatma.dedeoglu@childrens.harvard.edu
Melissa Oliver  msoliver@iu.edu
Polly Ferguson  polly-ferguson@uiowa.edu
Dan Zhao  yongdong.zhao@seattlechildrens.org
Localized Scleroderma
Tuesday, April 28 - 1:30pm - 3:00pm
Investigators, fellows, coordinators and patients with interest in juvenile localized scleroderma (morphea) are all welcome. Preliminary information from the SCORE CARRA jLS registry will be presented. Encouragement of the jLS CTP study methotrexate and more recent mycophenolate mofetil arm discussed. These will help prime us for clinical drug trials, including ongoing efforts for biologic trials. Translational and clinical science updates on LS will also be discussed.
Kathryn Torok  kathryn.torok@chp.edu
Suzanne Li  suzanne.li@hackensackmeridian.org
Brandi Stevens  stevenbe@iu.edu

PFAPA
Tuesday, April 28 - 1:30pm - 3:00pm
We will be working on the International effort to validate the Autoinflammatory Disease Activity score in PFAPA. Another area of focus will be implementation of the Comparative Effectiveness Studies utilizing Consensus Treatment Plans developed for PFAPA including questionnaire completion/technological innovations for fever tracking. We will continue to advance enrollment in iThemmonitor monitoring of fever curves in PFAPA.
Sivia Lapidus  sivia.lapidus@hackensackmeridian.org
Fatma Dedeoglu  fatma.dedeoglu@childrens.harvard.edu
Grant Schulert  grant.schulert@cchmc.org
Kalpana Manthiram  kalpana.manthiram@nih.gov

Inflammatory Brain Disease
Tuesday, April 28 - 5:30pm - 7:00pm
We will be reviewing the updated BrainWorks registry expanded to capture data relevant to AE. We will examine if missing elements and finalize the database. We will also review the acceptance of this registry under CARRA IRB and how to enroll patients.
Heather Van Mater  heather.vanmater@duke.edu
Eyal Muscal  emuscal@bcm.edu
Elizabeth Wells  ewells@childrensnational.org
Marinka Twilt  marinka.twilt@ahs.ca

PFAPA/Autoinflammatory Disease Parent Advocacy
Tuesday, April 28 - 5:30pm - 7:00pm
We will work on the continued development of the Autoinflammatory program network including creating an infrastructure for clinical and translational projects. Current efforts are to capture the demographics and Autoinflammatory diseases seen in North American programs who are part of this network. The Autoinflammatory Advocacy group will be advancing patient educational modalities and a patient initiated registry.
Sivia Lapidus  sivia.lapidus@hackensackmeridian.org
Fatma Dedeoglu  fatma.dedeoglu@childrens.harvard.edu
Karen Durrant  karen@autoinflammatory.org
Grant Schulert  grant.schulert@cchmc.org
Kalpana Manthiram  kalpana.manthiram@nih.gov
Systemic Sclerosis  
Tuesday, April 28 - 5:30pm - 7:00pm  
Investigators, fellows, coordinators and patients with interest in juvenile systemic sclerosis (scleroderma) are all welcome.  
Preliminary information from the SCORE jSSc registry will be presented. Treatment updates in adult SSc discussed at the ACR this year will be reviewed, which are applicable to jSSc. Quality of life study updates and translational science updates will also be discussed.  
Kathryn Torok  kathryn.torok@chp.edu  
Suzanne Li  suzanne.li@hackensackmeridian.org  
Brandi Stevens  stevenbe@iu.edu  

Childhood Sjogren's Syndrome  
Wednesday, April 29 - 8:45am - 11:45am  
1) Discuss starting a CTP for recurrent parotitis and childhood Sjögren's Syndrome  
2) Discuss the treatments used for childhood Sjogren’s Syndrome/ recurrent parotitis – current published data and lack publications for off labeled treatments  
3) Continue to hone the prospective registry and discuss logistics  
Sara Stern  sara.stern@hsc.utah.edu  
Matthew Basiaga  matthew.basiaga@seattlechildrens.org  
Scott Lieberman  scott-lieberman@uiowa.edu  

Kawasaki Disease  
Wednesday, April 29 - 8:45am - 11:45am  
CARRA KD workgroup focuses on developing a CTP for refractory KD with an ultimate goal of improving treatment and outcome. There is known variation in practice patterns and treatment across CARRA sites. We developed cases that are incorporated into a survey focusing on treatment of refractory KD patients. During the refractory KD WG meeting, the group will have a literature review, finalize/ analyze the survey and use this information to begin process of CTP development.  
Cagri Yildirim Toruner  cagri.toruner@nationwidechildrens.org  
Robert Sundel  robert.sundel@childrens.harvard.edu  
Bianca Lang  bianca.lang@dal.ca  
Ali Yalcindag  ayalcindag@lifespan.org  
Sivia Lapidus  sivia.lapidus@hackensackmeridian.org  

Translational Research and Technology Committee  
Main Session  
Monday, April 27 - 8:00am - 12:00pm  
The Translational Research and Technology Committee (TRTC) seeks to help CARRA become an engine of translational research in the pediatric rheumatic diseases. Our goals are accomplished through maintaining a thriving CARRA biorepository, assisting other CARRA disease specific work groups in developing translational arms to CTPs and related studies, and identifying funding to conduct high level data analysis (genomics, transcriptomics, metabolomics, etc.….) on biosamples collected through CARRA.  
Peter Nigrovic  pnigrovic@bwh.harvard.edu  
Lauren Henderson  lauren.henderson@childrens.harvard.edu  

Wrap-Up  
Wednesday, April 29 - 8:45am - 9:45am  
Peter Nigrovic  pnigrovic@bwh.harvard.edu  
Lauren Henderson  lauren.henderson@childrens.harvard.edu