Session Information

2017 CARRA Annual Scientific Meeting
Marriott Marquis Houston
May 15-17, 2017

When registering for the Annual Meeting, attendees can select the Workgroup sessions they would like to participate in. Registration is limited to one session per timeslot. Eligibility to participate varies by session. Parent/Patient and Research Coordinators are eligible to attend all sessions. Some sessions encourage the active participation of Parent/Patient and Research Coordinator attendees. Those sessions are marked with (P) and/or (C). Industry are eligible to attend only the sessions indicated with an (I) (Pre-conference meetings are not open to Industry). Please review the session indicators when making your selections.

(I) Industry may attend (P) Parent/Patient participation encouraged (C) Research Coordinator participation encouraged

Monday (8:00 AM – 3:00 PM) Pre-Conference Meetings

Early Investigators Meeting

Session Leaders
Jay Mehta, mehtaj@email.chop.edu
Kristen Hayward, kristen.hayward@seattlechildrens.org

Aims/Goals: Are you a young CARRA member who is looking to get help with moving your career forward? The Early Investigator meeting will bring together your colleagues to provide didactic sessions along with ample networking opportunities. You will get to learn about the work your colleagues are doing, create collaborations, and hear from successful senior CARRA members on how they overcame struggles in their career. If you are doing any amount of research, from enrolling patients in a registry to developing investigator-initiated grant-funded projects, you will benefit from attending this meeting.

Participants: Registration for this session is open to all CARRA Early Investigators (completed fellowship from June 2010 to present) and current 3rd year fellows

---

Research Coordinators Pre-Conference Meeting

Session Leaders
Jennifer Woo, woojm@uwm.edu

Aims/Goals: The Research Coordinators Pre-Conference meeting is open to all CARRA Research Coordinator (Associate) members. This session is designed to encourage networking among CARRA study coordinators and to foster the coordinator community within CARRA. Research Coordinators who attend this meeting will learn about opportunities within the CARRA Coordinator network, contribute to the shaping of the growing CARRA coordinator network, and gain insightful knowledge to succeed as a research coordinator in pediatric rheumatology. Topics include: Research Protocol Development, JIA and Joint Count Learning session, Practicing Effective Mentoring, Coordinator Town Hall, and Planning for the Year Ahead.

Participants: Registration for this session is open to all Research Coordinator (Associate) Members. Others interested in helping the CARRA Coordinator network grow are also welcome.

CARRA Fellows Career Development Workshop

Session Leaders
Jennifer Cooper, Jennifer.Cooper@ucsf.edu
Kathryne Phillippe, kate.c.phillippi@gmail.com

Aims/Goals: This focus of this session is to prepare pediatric rheumatology fellows to transition to attending rheumatologists. Lecture topics will include Work-Life Balance, CV preparation, Job Search Strategies, Contract Negotiation, and tips for Building a Successful Research Career.

Participants: Registration for this session is open to 2017 Pediatric Rheumatology Fellows only.

Introduction to MSK Ultrasonography for Rheumatologists (Hands On) ***(9:00 AM – 12:00 PM)***

Session Leaders
Ed Oberle, edward.oberle@nationwidechildrens.org
Johannes Roth, jroth@cheo.on.ca

During this workshop participants with no prior hands on experience in MSK ultrasonography will be offered an introduction to the basics of MSK ultrasonography. The workshop will consist of an introductory lecture followed by hands on scanning on healthy adults.

Participants: Registration for this session is open to CARRA Members with no prior hands on experience in MSK ultrasonography (Limited to 15 attendees)

Parent/Patient Orientation ***(3:00 PM-3:50 PM)***

Session Leaders
Vincent Delgaizo, vdelgaizo@comcast.net
Melanie Kohlheim, mkohlheim@gmail.com
Suz Schandt
Emily von Scheven, evonsche@ucsf.edu

Orientation for parents/patients attending the CARRA conference. Workgroup leaders who are encouraging parent/patient participation in their meetings are invited to attend and discuss their meeting.

Participants: Parents, Patients, and Workgroup leaders who are encouraging parent/patient participation in their meetings.

CARRA Registry Meeting for Investigators and Coordinators ***(4:00-5:30 PM)***

Session Leader
Jason Jones, jjones@carragroup.org

The interactive Registry Meeting for Registry Investigators and Coordinators will focus on Registry/CTP recruitment, challenges and best practices. The meeting will utilize a dynamic panel discussion followed by a breakout session where key questions will be discussed and summarized.

Participants: Site personnel (all investigators, fellows and coordinators) at current CARRA Registry Sites. CARRA members from non-Registry sites and parents may attend as well.

Tuesday (2:30 PM - 5:30 PM) Concurrent Workgroup Session #1

(JDM) Priorities and the Future for JDM and CARRA

Session Leaders
Adam Huber, adam.huber@iwk.nshealth.ca
Susan Kim, susan.kim@ucsf.edu

Aims/Goals: The goal of this group is to begin the process of charting the future direction of research within the JDM Committee. These discussions will be informed by similar discussions which are planned for the 2nd Global Conference on Myositis, which will be held shortly before the CARRA Annual Meeting. This work will necessarily also consider how the JDM Committee functions, and how the leadership can best facilitate the work that is being done, and communicate this information to all interested members. It is anticipated that this process will include input from a variety of stakeholders, including physician and allied health professional members of CARRA, research coordinators, patients and families. **Agenda**: 1. Review recently published Clinical Treatment Plans in JDM 2. Review proposal for inclusion of JDM in the CARRA registry, including proposed data fields 3. Break-outs to discuss research priorities in JDM and for the JDM Committee of CARRA

(I) Industry may attend (P) Parent/Patient participation encouraged (C) Research Coordinator participation encouraged

---

(JIA) Inactive Disease

Session Leaders
Daniel Horton, daniel.horton@rutgers.edu,
Sarah Ringold, sarah.ringold@seattlechildrens.org

Aims/Goals: To plan and conduct research on approaches to managing inactive JIA and outcomes after treatment withdrawal. **Agenda**: Complete surveys on clinical approaches to withdrawing therapy for children with inactive JIA Review recent literature on withdrawing therapy for well-controlled arthritis Review ongoing work by the inactive disease workgroup, including a draft of a proposal for a prospective, multicenter study on treatment withdrawal Break out into small groups to (1) critique the study proposal and (2) discuss new research ideas on studying inactive disease Reconvene to hear from the small groups and discuss ideas generated

(I) Industry may attend (P) Parent/Patient participation encouraged (C) Research Coordinator participation encouraged

---

(JIA) Ultrasound Session #1: Review of Knee Scoring System

Session Leaders
Ed Oberle, edward.oberle@nationwidechildrens.org
Johannes Roth, jroth@cheo.on.ca

Aims/Goals: The workgroup aims to develop standardized, methodical MSKUS protocols for image acquisition and scoring to help with clinical management as well as outcome measures in research. At the CARRA meeting this year, our goals are to: 1. Finalize work done on the knee. We have developed standardized views and a scoring system for grading knee effusions. Will have large group collaborative session on critiquing and grading images collected by the group at large. 2. Begin work on developing new algorithms/scoring systems for additional joints. 3. We hope to have machines and patients with active disease to be able to validate the standardized views and scoring systems with an inter-rater reliability exercise. ***note - there will not be any specific ultrasound education during these sessions.
Agenda: 1. Review and critique images collected by group members regarding imaging scoring system and algorithm for knee assessment of arthritis/effusions. 2. Break out review on new joints to include in scoring system and standardized views. 3. Standardization exercise with ultrasound machines and local patients.

(I) Industry may attend (C) Research Coordinator participation encouraged

---

(JIA) Uveitis

Session Leaders
Egla Rabinovich, egla.rabinovich@duke.edu
Sheila Angeles-Han, Sheila.Angeles-Han@cchmc.org
Mindy Lo , Mindy.Lo@childrens.harvard.edu

Aims/Goals: The goal of the Uveitis Workgroup is to improve outcomes of children with pediatric non-infectious uveitis. 1. Develop treatment plans to optimize outcomes of inflammatory uveitis. 2. Develop research strategies to examine long term outcomes in inflammatory uveitis, including response to therapies, quality of
life and function. **Agenda**: 1. Provide information on Uveitis CTP and assess feasibility, interested sites and potential funding for implementation 2. Discuss feasibility of a CTP for TNF failures 3. We are considering to break out into smaller groups vs. remaining a big group for these projects (depending on interest and members wanting to lead effort): a) Quality of life/outcomes - validating EYE-Q instrument; b) Improving understanding of families/patients about uveitis; c) CTP for TNF failures; d) Uveitis surveillance. We are in process of identifying other topics and leaders for these groups.

(Pain) Pain Session #1: Chronic Widespread Pain in JIA (2hrs) & Online Pain Curriculum (1hr)

Chronic Widespread Pain in JIA

Session Leaders

Melissa Tesher,
mtesher@peds.bsd.uchicago.edu Jen Weiss,
Jennifer.weiss@hackensackmeridian.org Tracy
Ting, Tracy.Ting@cchmc.org
Brent Graham, brent.graham@vanderbilt.edu

Aims/Goals: 1. Evaluate the utility of the Pain Symptom Assessment Questionnaire (PSAQ) in identifying JIA patients with Juvenile Fibromyalgia (JFM), in comparison to the Yunus and Masi criteria for JFM1. 2. Identify differences amongst JIA patients with and without JFM including demographic data, disease characteristics, functional disability, and physician and patient/parent global assessments. **Agenda**: Last year, this project was conceived and planned at the annual meeting. This year we will discuss the following: 1. IRB approvals (if not all complete prior to the meeting)- barriers, roadblocks, strategies 2. Feedback based on initial utilization of the surveys in JIA patients; any unanticipated problems in data collection will be discussed

(C) Research Coordinator participation encouraged

Online Pediatric Pain Curriculum

Session Leader

William Bernal, william.bernal@ucsf.edu

Aims/Goals: The aim of this workgroup is to develop the Musculoskeletal Pain module of the Online Pediatric Pain Curriculum (OPPC), a project aimed at educating health care students and professionals about pediatric pain. The goal of the OPPC is to improve pediatric pain assessment and management. The main goal of the meeting is to plan the assessment phase of the module to evaluate its impact. **Agenda**: - Review of finalized document for MSK Pain module of Online Pediatric Pain Curriculum - Planning for assessment phase of module: survey plan, identification of participants and stakeholders.

(SLE) SLE Dermatology

Session Leaders

Lisa Arkin, larkin@dermatology.wisc.edu
Kaveh Ardalan, kardalan@luriechildrens.org

Aims/Goals: Aims for the SLE Dermatology Work Group: 1. To define high priority research questions for clinicians caring for children with cutaneous lupus erythematosus (CLE) 2. To create opportunities for collaboration between pediatric rheumatologists and dermatologists managing children with cutaneous lupus 3. To collect retrospective and prospective observational data to inform the creation of collaborative consensus treatment plans for children with cutaneous lupus.

Agenda: 2017 SLE Dermatology Work Group Meeting Agenda: 1. Update on Retrospective DLE Cohort Study - review of aims, case report forms, manual of operations, opportunity to join 2. SLE Dermatology photo atlas - feedback 3. Categorization of subtypes of CLE and distinguishing features in adults and children (Vicky Werth, Ben Chong) 4. Review of CARRA CLE registry forms & implementation 5. Discussion of gaps in the CARRA CLE Registry - wish list of additional needs, discussion of grant writing effort to fund them.

(I) Industry may attend (P) Parent/Patient participation encouraged (C) Research Coordinator participation encouraged

---

(SVARD) Juvenile Scleroderma Working Group Meeting (SCORE CARRA Study Overview/Training) #1

Session Leaders
Kathryn (Cassie) Torok,
Kathryn.torok@chp.edu Suzanne Li,
Suzanne.Li@hackensackmeridian.org Anne
Stevens, anne.stevens@seattlechildrens.org

Aims/Goals: Overall goals: Collaborate with 16 CARRA sites interested with enrolling jLS and jSSc subjects to pilot scleroderma-specific CTPs for CARRA database using REdCap to migrate to RAVE at end of study. Collect jSSc and jLS biospecimens throughout visits; every 6 months for 2 years (5 visits); for future research and immunophenotyping **Agenda**: Brief overview of SCORE CARRA study and organizational/contact pathway • Review finalized CRFs for Red Cap DB entry for : -common forms -LS specific -SSc specific - Review 2 cases study subject's data entry - review lab collection process and shipment • Time/organization permitting may have patients for skin scoring

(P) Parent/Patient participation encouraged (C) Research Coordinator participation encouraged

---

(SVARD) Kawasaki DIsease

Session Leaders
Robert Sundel, robert.sundel@childrens.harvard.edu
Rae Young, rae.yeung@sickkids.ca
Sriharsha Grevich, Sriharsha.grevich@seattlechildrens.org

Aims/Goals: Ultimately we would like to establish the arms of two CES's, one for treatment of children who remain febrile despite treatment with IVIG, and one for children who are at high risk of failing to respond to the first dose of IVIG. **Agenda**: Finalize plans for a CTP's to determine which if the most effective of the current approaches to treatment of children with a high risk of failing to respond to IVIG, and treatment of children who remain febrile despite treatment with IVIG.

(TRTC) TRTC Session 1

Session Leaders
Peter Nigrovic, Peter.nigrovic@childrens.harvard.edu
Lauren Henderson, Lauren.Henderson@childrens.harvard.edu
Jim Jarvis, jamesjar@buffalo.edu

Aims/Goals: The Translational Research and Technology Committee (TRTC) seeks to help CARRA become an engine of translational research in the pediatric rheumatic diseases. TRTC Session 1 provides updates from each workgroup since last year, include discussion of TRTC member survey results from November 2016. **Agenda**: 1) Introduction 2) TRTC Survey Results 3) Update from governance working group 4) Data & Sample Access Committee 5) Update from Archiving workgroup 6) Biobank working group.

(I) Industry may attend (P) Parent/Patient participation encouraged (C) Research Coordinator participation encouraged

---

(TRANS) Transition

Session Leaders
Erica Lawson, erica.lawson@ucsf.edu,
Aimee Hersh,
Aimee.Hersh@hsc.utah.edu, Peter
Chira, pchira@ucsd.edu

Aims/Goals: The overall aim of the CARRA Transition Work Group is to understand and improve health care quality, patient engagement and health outcomes during the transition from pediatric to adult rheumatology care. **Agenda**: 1) Medical College of Wisconsin Transition program: Betsy Roth-Wojcicki to present state-funded transition improvement initiative. 2) Development of rheumatology clinic-based transition tools in collaboration with SPARK healthcare 3) Arthritis Foundation iPeer to Peer virtual peer mentoring program: Roll-out & outcomes study 4) How to promote transition improvement in your community 5) Break out groups: a. Virtual focus group study to assess transition needs of patients and parents b. How to implement transition improvement via your EMR c. Development of transition/self-management QI process in collaboration with PR- COIN.

(I) Industry may attend (P) Parent/Patient participation encouraged

---

Wednesday (7:00 AM – 8:00 AM)

Small Centers

Session Leaders
Peter Blier, Peter.Blier@baystatehealth.org
Theresa Wampler-Muskardin, WamplerMuskardin.Theresa@mayo.edu

Session Description: This meeting is open to CARRA members (investigators, fellows, nurses, coordinators) from “small centers” and members who feel challenged to participate in research due to barriers/restrictions at their site. A small center is a site that has 3 or fewer pediatric rheumatologists. We encourage you to attend and discuss challenges related to participating in research at small centers.

The agenda will include: new initiatives to enhance communication between members; a discussion of opportunities for beginning participation in the new Registry, and identifying barriers to full participation by currently active members; how to participate in non-Registry research in CARRA; solving the problem of feeling "out of the loop" in CARRA.

(C) Research Coordinator participation encouraged

Wednesday (8:15 AM - 11:15 AM) Concurrent Workgroup Session #2

(JDM) Dermatology Rheumatology JDM Work group: Measures of Cutaneous Disease Activity

Session Leader
Susan Kim, susan.kim@ucsf.edu

Aims/Goals: Partnership with pediatric dermatology and rheumatology in the care of patients with autoimmune skin disease, to improve assessment, care and outcomes. 1. To identify priority research questions for clinicians caring for children with the cutaneous manifestations of juvenile dermatomyositis (JDM). 2. To foster and develop opportunities for collaboration between pediatric dermatologists and rheumatologists, to improve assessment, care and outcomes of children with JDM. **Agenda**: Skin scoring measures to measure disease activity in Juvenile Dermatomyositis. 1. Dr. Vicky Werth, Dr. Adam Huber and Dr. Kaveh Ardalan will review the background and administration of the currently available JDM skin scoring tools (CDASI, a-CAT and skin DAS). 2. Group discussion re: pros and cons of these three skin scoring tools for use in clinical and research settings. 3. Defining next steps to come to consensus re: skin scoring measure to incorporate into the CARRA JDM registry, with identification of grant opportunities to fund this work.

(I) Industry may attend (P) Parent/Patient participation encouraged

---

(JIA) Systemic Juvenile Idiopathic Arthritis (sJIA)

Session Leaders
Karen Onel, onelk@hss.edu
Susan Shenoi, susan.shenoi@seattlechildrens.org
Kabita Nanda, kabita.nanda@seattlechildrens.org

Aims/Goals: Help to define optimal care for children with Systemic JIA with focus on defining how and when to stop medication when children are in remission as well as considering new treatment protocols for children who continue to have active disease despite standard therapies. **Agenda**: Review results of pilot study evaluating CARRA member treatment practices for stopping biologic therapies in Systemic JIA. Consider wider dissemination to larger CARRA group (JIA or entire CARRA) • Begin creation of consensus treatment plans to compare ways of stopping medications for patients in remission based on the above results • Discuss how to define and capture patients who fail standard therapy • Discuss how to leverage existing registry data to inform the above • Present update on cardiopulmonary study • Review definitions of inactive disease and consider
how to define failures

(I) Industry may attend (P) Parent/Patient participation encouraged

---

(JIA) Ultrasound Session #2: Practical exercise on applicability of Knee Scoring System

Session Leaders
Ed Oberle, edward.oberle@nationwidechildrens.org
Johannes Roth, jroth@cheo.on.ca

Aims/Goals: The workgroup aims to develop standardized, methodical MSKUS protocols for image acquisition and scoring to help with clinical management as well as outcome measures in research. At the CARRA meeting this year, our goals are to: 1. Finalize work done on the knee. We have developed standardized views and a scoring system for grading knee effusions. Will have large group collaborative session on critiquing and grading images collected by the group at large. 2. Begin work on developing new algorithms/scoring systems for additional joints. 3. We hope to have machines and patients with active disease to be able to validate the standardized views and scoring systems with an inter-rater reliability exercise. ***note - there will not be any specific ultrasound education during these sessions.
Agenda: 1. Review and critique images collected by group members regarding imaging scoring system and algorithm for knee assessment of arthritis/effusions. 2. Break out review on new joints to include in scoring system and standardized views. 3. Standardization exercise with ultrasound machines and local patients.

(I) Industry may attend

(Pain) Pain Session #2: FIT Teens Trial (2hrs) & iCanCope App Dissemination and Integration (45min)

FIT Teens Trial
Session Leader
Susmita Kashikar-Zuck, PhD, susmita.kashikar-zuck@cchmc.org

Aims/Goals: The overall aims of the workgroup are to implement a 7-site randomized clinical trial evaluating the efficacy of the FIT Teens program for juvenile fibromyalgia. The U34 planning phase has been completed and
the participating CARRA sites will begin implementing the study as soon as funding is received (NIAMS U01 Cooperative Agreement). Once the study begins, the infrastructure for the trial will provide a rich resource for ancillary studies and additional collaborative projects for CARRA members interested in chronic pain in the rheumatic diseases. **Agenda**: Discuss milestones achieved during the U34 clinical trial planning period Present overview of study design and procedures for the 5-year FIT Teens RCT Logistical planning for the U01 clinical trial and setting of timelines for study initiation at each participating site Site communication plan Planning for ancillary studies and data sharing

iCanCope App Dissemination
Session Leader
Mark Connelly, mconnelly1@cmh.edu

Aims/Goals: The overall goal of this project is to demonstrate feasibility for using the CARRA resources (primarily the registry) to (a) facilitate dissemination of (mobile) pain self-management tools, and (b) support integration of mobile pain data with patient's other data in the registry for secondary analyses and long-term outcome analyses. This is a grant-funded project (supported primarily by AHRQ) that is an

extension of other work completed by the pain committee during prior meetings (e.g., prior consensus conference on the pain self- management algorithm and strategies to be used for the mobile app). **Agenda**: (1) Provide updates about project status and achievements thus far (2) Discuss procedures for patient enrollment and solicit sites for participation

(C) Research Coordinator participation encouraged

(SLE) SLE Nephritis

Session Leaders
Natasha Ruth, ruthn@musc.edu
Scott Wenderfer,

Aims/Goals: -To improve outcomes in patients with lupus nephritis in cSLE -To promote evidence based practices for treating lupus nephritis in cSLE -To identify and promote consensus where appropriate in the management of lupus nephritis in cSLE -To develop infrastructure necessary to study issues regarding lupus nephritis in cSLE when consensus is not possible -To continue to utilize a multidisciplinary approach when studying management, treatment and outcomes in lupus nephritis in cSLE. **Agenda**: Discuss ongoing projects including: 1) Cellcept Withdrawal Prospective Study - review time line, data collection, analysis and manuscript plans 2) Class V lupus nephritis Review 3) Refractory Class IV lupus nephritis - discuss recent survey and future directions Discuss and develop future projects including: 1) Adherence and lupus nephritis outcomes 2) Multidisciplinary lupus clinics and lupus nephritis outcomes At the end of the session, we expect that there will be a scientific leader/co-leaders along with a team of members dedicated to the study design, data collection, analysis and manuscript preparation for each study above. A timeline will be developed to outline goals and objectives and plans for completion of each study. Time will also be dedicated to the introduction of new studies so we ask individuals coming to the group to prepare brief 5 minute summaries of any studies that they would like to introduce to this work-group.

(P) Parent/Patient participation encouraged (C) Research Coordinator participation encouraged

---

(SLE) Antiphospholipid Syndrome

Session Leader
Barry Myones, bmyones51@gmail.com

Aims/Goals: To coordinate efforts with the Pediatric APS International Task Force in the identification of unanswered questions in Pediatric APS, the development of specific research questions that can be addressed by CARRA, and to facilitate projects that gather data to answer these questions within the CARRA community.

Agenda: Summary of April 2016 APS sub-group meeting (35 attendees) including goals/priorities set by group, i.e. cases, registry, surveys. Review of progress on goals to date. Review of Pediatric APS Task Force sessions at September 2016 APS meeting in Cyprus. Summary of progress of the European community and the provisional pediatric APS criteria by the SHARE initiative. Discussion of how CARRA will proceed, i.e. separate/parallel development of criteria versus joining European effort (makes more sense). How will we interface? What is the interest? Surveys of interested CARRA members and resources (presentation and discussion at meeting). Assess usefulness of existing North American registries to the SHARE initiative (combined assessment with PRINTO group will be necessary- before and

after CARRA session). Assembly of cases for validation of provisional criteria (discuss case template and revise at session). Discussion of possible involvement in treatment protocols through the Pediatric Hematology/Thrombosis network.

(P) Parent/Patient participation encouraged

(SVARD) Inflammatory Brain Disease

Session Leaders

Heather Van Mater, heather.vanmater@duke.edu
Eyal Muscal, emuscal@bcm.edu
Susanne Benseler, susanne.benseler@albertahealthservices.ca

Aims/Goals: We have made good progress in engaging a group of neurologists, psychiatrists and rheumatologists. We have developed a diagnostic algorithm (in final draft), standardized workup, and initiated discussions about initiating a large multicenter study through BrainWorks to develop the pilot data for future treatment trials. Over the next year, we hope to: 1. assess consensus on the workup for Inflammatory Brain Diseases with our larger working group consisting of neurology and psychiatry in addition to rheumatology 2. enhance the fields in BrainWorks to encompass the diagnostic evaluation, outcome measures and treatments
we plan to investigate in the study of AE patients 3. Investigate neuropsychiatric evaluations that currently exist and determine which combinations of existing validated measures should be incorporated in our assessment tools and outcome measures (in collaboration with the neuropsychologists we have on our larger working group now) 4. Start to enroll patients in BrainWorks once the above is complete to start to explore treatment strategies providers are currently using and associated outcomes to build on as we work toward consensus treatment plans and treatment trials (trials an important initiative of neurology). **Agenda**: 1. Review highlights from Novembers multidisciplinary meeting in DC and future directions. a. Discuss priorities of that group and ensure our CARRA working group (many of whom were also at the DC meeting) are in agreement on priorities for this coming year. b. Review final recommendations for the workup and determine how to proceed in determining consensus for rheumatology and neurology to move this project toward publication. For example- survey all of CARRA, AE/Inflammatory Brain Disease experts in the multidisciplinary working group, etc c. Review recommended fields to add to Brainworks and identify members to work on finalizing that project. 2. Resources: a. review resources collected over the last year and determine how to best make these available. b. identify members to develop missing resources 3. Rehab. This was identified as a significant need by families and providers alike. Determine the feasibility of our group investigating and developing potential guidelines for services, adjunct therapies, resources, etc for patients during the recovery phase of the disease.

(P) Parent/Patient participation encouraged (C) Research Coordinator participation encouraged

---

(SVARD) PFAPA Work Group

Session Leaders

Sivia Lapidus, sivia.lapidus@atlantichealth.org
Kalpana Manthiram, kalpana.manthiram@nih.gov
Fatma Dedeoglu, Fatma.Dedeoglu@childrens.harvard.edu
Gil Amarilyo, gamarilyo@clalit.org.il

Aims/Goals: 1. Finalize and implement consensus treatment plans (after distributed CARRA-wide) . 2. Foster patient engagement through development of fever/symptom tracking tools 3. Support translational projects through development of bio-sample collection 4. Encourage development of collaborative auto- inflammatory centers in North America. **Agenda**: -Focus on data collection of PFAPA patients (patient and physician data-entry), which will include patient entered data and technology to facilitate this - Autoinflammatory Network Development -Refine translational goals and sample collection for future bio- repository -Achieve consensus among the PFAPA WG in terms of patient characteristics to include in finalized CTP.

(P) Parent/Patient participation encouraged (C) Research Coordinator participation encouraged

---

(SVARD) Juvenile Scleroderma Working Group Meeting (General Research Updates: jLS and jSSc) #2

Session Leaders

Kathryn (Cassie)Torok,
Kathryn.torok@chp.edu Suzanne Li,
Suzanne.Li@hackensackmeridian.org Anne
Stevens, anne.stevens@seattlechildrens.org

Aims/Goals: Overview of juvenile Localized Scleroderma (jLS) and juvenile Systemic Sclerosis (jSSc) patient evaluation, discussion of validating SSc classification criteria, patient reported outcomes, and treatments for SSc and difficult LS.
Agenda: This session will discuss different topics related to jLS and jSSc. 1. There will be a brief workshop on jLS and jSSc skin and ECM examination with patient volunteers. 2. Discussions will focus on jSSc classification criteria with a review of existing proposed criteria (pediatric and adult) and available jSSc data, and steps we should take to validate criteria. 3. Other topics for discussion will be patient reported outcomes, previously studied and potential others to evaluate, and 4. Discussion of treatment strategies for jSSc and difficult jLS subjects to potentially work towards standardizing some regimens for future evaluation.

(P) Parent/Patient participation encouraged (C) Research Coordinator participation encouraged

---

(TRTC) TRTC Session 2

Session Leaders
Peter Nigrovic, Peter.nigrovic@childrens.harvard.edu
Lauren Henderson, Lauren.Henderson@childrens.harvard.edu
Jim Jarvis, jamesjar@buffalo.edu

Aims/Goals: The Translational Research and Technology Committee (TRTC) seeks to help CARRA become an engine of translational research in the pediatric rheumatic diseases. TRTC Session 2 will focus on barriers and opportunities, including small group brainstorming and troubleshooting, as well as brief presentations of resources available for member research. **Agenda**: 1) Short talks and panel discussion on big data research. 2) Breakout Groups-How can TRTC help translational investigators? 3) Specific opportunities/updates: a. Biospecimen collection in STOP and FROST. b. SCORE. c. UCAN CAN-DU d. CCHMC P30 e. Joint Biology Consortium f. Public-private partnership?

(I) Industry may attend (P) Parent/Patient participation encouraged (C) Research Coordinator participation encouraged

---

Wednesday (1:00 PM - 4:00 PM) Concurrent Workgroup Session #3

(JDM) Biologics in JDM-CTP

Session Leader
Chuck Spencer, charles.spencer@nationwidechildrens.org

Aims/Goals: Develop the CTP protocol for biologics in full detail Make decisions on crucial issues Decide on whether to write a manuscript on the CTP plans for late 2017 (previous biologic manuscript to be submitted in early 2017) Choose 3 individuals to write the protocol Pick a target date for initial protocol to be finished and circulated among workgroup members from 2017-2018 Discuss commitments to be in CTP by 2018 Pick target date for applying for funding with or without other JDM CTP's-2018 to 2019 Choose Executive Committee for this CTP by 2018 CARRA. **Agenda**: 20 people-3 hours Review of previous CTP in JDM Review of current state of decisions on a. duration of CTP and potential dates to start b. inclusion criteria of CTP c. exclusion criteria of CTP d. biologics to be studied e. arms of study and dynamics of switching from biologic to biologic f. # of centers needed for how many patients g. combining with other JDM CTP's in sharing data base and funding h. funding targets-Cure JM; Myositis Association; NIH.

(P) Parent/Patient participation encouraged (C) Research Coordinator participation encouraged

---

(JDM) Calcinosis in JDM

Session Leaders
Mark Hoeltzel, mhoeltze@med.umich.edu
Amir Orandi,

Aims/Goals: Goals: 1. Develop a CTP for the treatment of calcinosis associated with JDM. 2. Better characterize the complication of calcinosis in patients in JDM, including; epidemiology, risk factors, classification, diagnosis and staging, morbidity, treatment, and outcomes. **Agenda**: Review Work Group Goals Review Accomplishments to Date Discuss new/current projects Breakout Groups for Current Projects 1. Case-Based Survey - Treatment of JDM Calcinosis 2. Multi-Center Retrospective Review of JDM Calcinosis

---

(JIA) Spondyloarthritis

Session Leaders
Matthew Stoll, mstoll@peds.uab.edu
Hema Srinivasalu, HSriniva@childrensnational.org

Aims/Goals: We have two projects that we plan to pursue. The first, introduced during the 2016 meeting, is to better characterize children with predominant enthesitis and / or sacroiliitis. They typically have suggestive clues for spondyloarthritis, such as morning stiffness accompanied by pain and tenderness at entheseal locations. By definition, they lack significant joint swelling, have normal laboratory values, and often have minimal findings on advanced imaging studies; thus, they could easily be diagnosed as having amplified musculoskeletal pain syndrome (AMPS.) However, many of them respond well to immunosuppressive therapy, confirming clinical impressions of an inflammatory etiology. The goal of this study is to identify biomarkers associated this clinical phenotype. To do this, we will recruit at multiple centers children with enthesitis / sacroiliitis predominant spondyloarthritis, obtaining research blood at baseline, prior to initiation of immunosuppressive therapy. Controls will include healthy subjects, children with AMPS, and children with obvious inflammatory spondyloarthritis. Treatment will be as per standard of care at each institution. After 4 - 8 months, the subjects will be re-assessed clinically, and repeat research blood will be obtained. The details have yet to be finalized, but this will likely include a multiplex panel of cytokines. Comparisons will include baseline comparisons of all four groups, as well as longitudinal comparisons of children with enthesitis / sacroiliitis predominant spondyloarthritis to identify correlates of disease. We will also work on finalizing which entheseal points would be examined. The second study is to characterize children with ERA who have failed therapy with TNF inhibitors. Until recently, TNF inhibitors were the only class of biologics with demonstrable effectiveness in pediatric or adult spondyloarthritis, and thus they generally represent first-line biologic therapy in children with ERA. Although most patients respond well to TNF inhibition, not all do, failing either secondary to lack of effectiveness or adverse events. Some of the children who fail TNF inhibition are treated with second-line biologics, with recent data primarily in adults indicating that blockade of the IL-17 pathway may be of particular benefit in patients with spondyloarthritis. We will do literature review of adult SpA anti-TNF failures. We determine to study the juvenile SpA population (ERA, Psoriatic arthritis, and undifferentiated arthritis) who fail anti-TNF agents secondary to poor response. We will work on defining treatment response in terms of enthesitis/peripheral arthritis and sacroiliitis (role of JSpA disease activity index in this exercise); define anti-TNF failure (one agent versus more). We will finalize data points to be collected. We will also review the CARRA CRFs if required data points are included. **Agenda**: 1. To assess

clinically and obtain bio specimen from children with predominant enthesitis/sacroiliitis (Discussed during the last meeting). 2. To identify cohort of axial SpA who are TNF failures to determine any clinical/imaging predictors of non-response, as well as to summarize their response to ustekinumab or secukinumab.

P) Parent/Patient participation encouraged

(JIA) Ultrasound Session #3: Practical exercise on applicability of Knee Scoring System

Session Leaders
Ed Oberle, edward.oberle@nationwidechildrens.org
Johannes Roth, jroth@cheo.on.ca

Aims/Goals: The workgroup aims to develop standardized, methodical MSKUS protocols for image acquisition and scoring to help with clinical management as well as outcome measures in research. At the CARRA meeting this year, our goals are to: 1. Finalize work done on the knee. We have developed standardized views and a scoring system for grading knee effusions. Will have large group collaborative session on critiquing and grading images collected by the group at large. 2. Begin work on developing new algorithms/scoring systems for additional joints. 3. We hope to have machines and patients with active disease to be able to validate the standardized views and scoring systems with an inter-rater reliability exercise. ***note - there will not be any specific ultrasound education during these sessions.
Agenda: 1. Review and critique images collected by group members regarding imaging scoring system and algorithm for knee assessment of arthritis/effusions. 2. Break out review on new joints to include in scoring system and standardized views. 3. Standardization exercise with ultrasound machines and local patients.

(I) Industry may attend

(JIA) TMJ Arthritis Interest Group

Session Leader
Marinka Twilt, marinka.twilt@ahs.ca

Aims/Goals: Already a strong research group in Europe (euroTMjoint, leader also president of that group) Plan is to integrate euroTMjoint initiatives in CARRA and start CARRA initiatives. **Agenda**: Welcome to the group by group leader. Introduction group members and their special interest Introduction to euroTMjoint and TMJ amerce group by group leader. Discussion different studies performed at this moment and possible other groups.

(PAIN) Pain Session #3: Toolkit Development for Assessing Decision Support Interventions among Youth with JIA (1.5 hrs) & Development of a Decision Support Intervention for Pain Management Options in JIA (1.5 hrs)

Development of a toolkit of instruments to assess the need for and the effectiveness of decision support interventions among youth with JIA

Session Leaders
Karine Toupin April, ktoupin@cheo.on.ca
Jennifer Stinson, jennifer.stinson@sickkids.ca

Aims/Goals: Develop a toolkit of instruments to assess the need for and the effectiveness of decision support interventions among youth with juvenile idiopathic arthritis and their families in clinical practice (e.g., in order to determine the need for using a JIA pain decision support intervention and to assess its effectiveness).**Agenda**: 1. Describe the project 2. Describe results from the first phase of the project: (1) review of the instruments in the adult and pediatric literature 3. Obtain group feedback on the instruments to assess the need for and the effectiveness of decision support interventions among youth with juvenile idiopathic arthritis and their families

(P) Parent/Patient participation encouraged

Development of a decision support intervention for pain management options in JIA
Session Leaders
Karine Toupin April, ktoupin@cheo.on.ca
Jennifer Stinson, jennifer.stinson@sickkids.ca

Aims/Goals: Gain consensus on the format and content of a decision support intervention for pain management in JIA. **Agenda**: 1. Describe the project 2. Describe results from the first phases of the project: (1) evidence for pain management options for JIA; (2) decision-making needs of youth with JIA and; (3) feedback from key stakeholders to develop the prototype 3. Present the prototype of the decision support intervention 4. Obtain group feedback on the prototype and gain consensus on the final version of the prototype

(P) Parent/Patient participation encouraged

(SLE) SLE Mental Health

Session Leaders
Andrea Knight, knightan@email.chop.edu
Tamar Rubinstein, trubinst@montefiore.org

Aims/Goals: The goal of the SLE Mental Health Workgroup is to engage in research and development of interventions focused on improving mental health care for youth with lupus, and other rheumatologic conditions such as juvenile arthritis and dermatomyositis. The workgroup seeks to improve education, identification and treatment of comorbid mental health conditions for these youth. **Agenda**: 1) Patient/Parent Mental Health Survey Project- discussion of preliminary results, ACR abstract development, dissemination strategies 2) SLE Mood Screen Project - update/discussion of preliminary results, ACR abstract development 3) Development of Pediatric Rheumatology Mental Health Screening Guide 4) Guest Speaker- TBD

(SVARD) AAV-CTP

Session Leaders
Linda Wagner-Weiner, lww@uchicago.edu
David Cabral, dcabral@cw.bc.ca
Eric Yen, eyen911@gmail.com

Aims/Goals: 1. Finalization of the consensus treatment protocol for the management of children with anti-neutrophil cytoplasm antibody-associated vasculitis. 2. We will start to work on logistics and plans for the launch the AAV-CT Multi-Center Study. **Agenda**: Provide an overview of our project and progress to date • Finalize our AAV Consensus Treatment Plan • Present our plans to formally study the effectiveness of the Pediatric
Vasculitis Activity Score (PVAS) Training Video in improving accurate grading of AAV patients' disease activity. • Recruit workgroup members to participate in the PVAS Training Video study • Strategize future plans, specifically focusing on the launching of the AAV CTP Multi-Center Study

---

(SVARD) CNO/CRMO

Session Leaders
Yongdong (Dan) Zhao, yongdong.zhao@seattlechildrens.org
Polly Ferguson, polly-ferguson@uiowa.edu
Fatma Dedeoglu, Fatma.Dedeoglu@childrens.harvard.edu

Aims/Goals: To bring together the expertise and experience of pediatric rheumatologists within CARRA, pediatric radiologists and international experts to improve/promote clinical and translational research in chronic nonbacterial osteomyelitis (CNO) through consensus treatment plans (CTP), comparative effectiveness research and biomarker discovery. • To partner with families to improve awareness of CNO/CRMO and to develop patient reported outcome measurements. **Agenda**: • Planning of the CARRA registry for children with NSAID-refractory CNO and/or active spinal lesions based on newly developed CTPs • Discussion of MRI reporting tool for CNO (we would like to invite a pediatric radiologist who has collaborated on developing this tool with CNO group leaders) • Discussion of setting up biorepository for CNO for biomarker research

(I) Industry may attend (P) Parent/Patient participation encouraged

---

(TRTC) TRTC Session 3

Session Leaders
Peter Nigrovic, Peter.nigrovic@childrens.harvard.edu
Lauren Henderson, Lauren.Henderson@childrens.harvard.edu
Jim Jarvis, jamesjar@buffalo.edu

Aims/Goals: The Translational Research and Technology Committee (TRTC) seeks to help CARRA become an engine of translational research in the pediatric rheumatic diseases. TRTC Session 3 looks forward to next steps for the TRTC, including interaction with the CARRA research committees and potential long-range projects. **Agenda**: 1) How can the TRTC help disease-specific committees? 2) The future – where are we going? 3) Wrap- up and agenda-setting.

(I) Industry may attend (P) Parent/Patient participation encouraged (C) Research Coordinator participation encouraged

---

(Med Ed Res) Medical Education Research

Session Leaders
Jay Mehta, mehtaj@email.chop.edu
Megan Curran, MCurran@luriechildrens.org
Kristen Hayward, Kristen.hayward@seattlechildrens.org

Aims/Goals: The mission of the CARRA Medical Education Research workgroup is to bring together educational scholars in pediatric rheumatology to develop collaborative studies and projects that improve education about pediatric rheumatic diseases. Educational research is increasingly recognized as important scholarly work within the field of pediatric rheumatology. In the last decade, 8 recipients of the competitive ACR Clinician Scholar Educator grants have been pediatric rheumatologists, including members of CARRA leadership. The CARRA Medical Education Research workgroup will provide an avenue for networking and collaboration that does not currently exist. This workgroup is an essential component of strategies to improve CARRA member engagement. Many CARRA members undertake educational research as part of their scholarly activity requirement and this workgroup could attract additional Pediatric Rheumatologists whose primary research interest is in medical education. Educational research projects to improve educational programming within fellowship programs will directly benefit CARRA as a means to disseminate information learned through CARRA-related research. Additionally, educational research targeting medical students and residents will increase awareness of pediatric rheumatology as a career choice and will improve physicians' ability to identify rheumatic disease allowing for more appropriate referrals and faster diagnosis. Ultimately, the efforts of the this workgroup would be firmly in line with CARRA's mission "to conduct collaborative research to prevent, treat, and cure rheumatic disease." **Agenda**: 1. Vision - Collaborative Educational Scholarship Discuss need for collaborative network, Criteria for Scholarship, Rationale/Fit with CARRA 2. Action - Fellow's BootCamp Initiative Divide into work groups by interest: Content, Delivery, Assessment 3. Conclusion - Timeline and Deliverables Share back from sub-work groups Discuss steps to move forward, project leads, future plans.