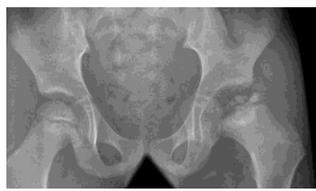


IPSG NEWSLETTER

Volume 1, Issue 1, Date March 8, 2013



No More Mushrooms!

Dear Members,

This is our 1st anniversary inaugural issue and we have come quite a long way just in 1 year. Much infrastructure for the study group has been laid down thanks to the efforts and contributions of many members. We have the 6-8 age group protocol finalized and you will soon receive the 8-11 and >11 group protocols to review and approve. Additionally, the IPSG website will go live in April so look forward to its arrival.

For next 6 months, we need to keep pushing forward and get everyone onboard with IRB approval and perfusion MRIs. As of today, 4 members have IRB approval and 9 have perfusion MRI capability. Congratulations on these accomplishments! As IRB approvals come in, we will provide you with access to IPSG database so that you can initiate patient enrollment.

Many thanks to everyone for your commitment to the IPSG and for your great effort to solve the Perthes mysteries.

Sincerely,

Harry Kim, IPSG Lead Organizer

Priority Items

1. *Get your local IRB Approval! Send a copy of your approval letters to Jamie Burgess (IPSG research coordinator).*
2. *Send your 1st perfusion MRI (deidentified) to TSRH (Jamie) for review.*
3. *Make sure research coordinators and administrative assistance receive this newsletter*

Contact Jamie Burgess if you have any questions.

Recent Accomplishments

- Congratulations to Tim Schrader and Rian Thorton, Pablo Castañeda, and Derek Kelly and Alice Moisan for successfully gaining their local IRB approval!
- Congratulations to Josh Hyman (PI) and his IPSG team members for receiving 2013 POSNA Clinical Trials Planning Grant to validate PROMIS-CAT instruments in patients with LCPD.

New Member Additions

- The IPSG has two new members! Please welcome Professor Ludwig Meiss from Hamburg and Professor Marek Synder from Poland.

6-8 Age Group Study—Ben Joseph, subgroup leader

- This prospective cohort study has 2 arms (nonoperative, symptomatic treatment arm and surgical containment arm).
- Based on the REDCap Survey, 42 members agreed to participate. We have 29 members who will enroll into the surgical containment arm and 13 members who will enroll into the nonoperative arm.
- For those of you with IRB approval and perfusion MRI capability, contact Jamie to access the REDCap database for enrollment.

8-11 Age Group Study—John Tis, subgroup leader

- This study will focus on the duration of postoperative non-weight bearing (NWB) after a surgical containment procedure. The 2 arms will be 6 weeks NWB vs 6 months NWB .
- If patient or parents do not wish to have surgery, the patient can be enrolled into MRI observational group.

>11 Age Group Study—Eduardo Novais, subgroup leader

- This study will compare the radiographic and functional outcomes of patients treated with multiple epiphyseal drilling and non-weight bearing to multiple epiphyseal drilling and hip arthrodiastiasis. There will also be a non-operative, MRI observational arm.

IPSG Website News—Jay Janicki, subgroup leader

- We will launch our IPSG website in April!
- The website subgroup (Jay Janicki, Ben Martin, Klane White, Harry Kim, and David Hebert) have been holding monthly conferences to develop interesting and informative content for the group's investigators and patients.

REDCap Database—Woody Sankar, subgroup leader

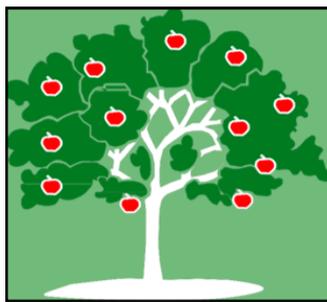
- The REDCap database for the 6-8 Study Protocol is almost ready to be moved into production. It is currently being piloted for multicenter usability. Those members with IRB approval and perfusion MRI capability will be given access soon to pilot the database.

Meet the IPSG Research Coordinator

Please note: all correspondence to Harry about the IPSG should cc Jamie as well.

Jamie Burgess is the new research coordinator for the IPSG and she recently received her PhD from Northwestern University in Chicago. She is happy to assist in any way possible so please do not hesitate to contact her. Please send IRB Approval letters, REDCap access requests, and research coordinator contact info to her.

Her email address is Jamie.Burgess@tsrh.org and her phone number is (214) 559-8569.

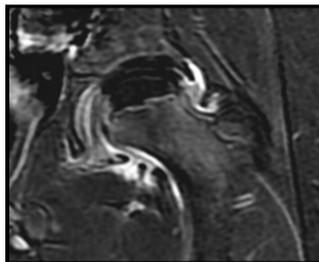


Upcoming Meetings:

- AAOS 2013 in Chicago, IL on March 22nd at 3pm—Please RSVP to Jamie
- POSNA 2013 in Toronto on May 1st at 9am at the Hospital for Sick Children. RSVPs will be sent soon.
- EPOS in Athens in April. If you are attending, please let Jamie know!

Numbers to date:

- **2 patients recruited!**
- **4 IRB approvals obtained!**
- **9 Perfusion MRIs approved!**



Perfusion MRI

- Thank you to Virginia Casey, Jennifer Laine, Simon Thomas, Benjamin Joseph, Woody Sankar, Ralf Stuecker, and Scott Rosenfeld for submitting a perfusion MRI
- Please send in a deidentified perfusion MRI if you have yet to do so to [TSRHhttps://community.tsrhc.org/page.aspx?pid=457](https://community.tsrhc.org/page.aspx?pid=457)

FAQ

Are we accepting any new members and how do they become a member?

We now have a Membership Committee (Kishore Mulpuri, chair) and membership application form. An applicant needs to submit a statement of interest, treat adequate number of patients in the initial stages of Perthes over 6 years of age, be able to obtain perfusion MRIs and IRB approval for research, and get approval by the membership committee. Members are also expected to attend the annual meeting at TSRH.

Recent Member Publications

- **Quantitative Measures for Evaluating the Radiographic Outcome of Legg-Calvé-Perthes Disease.** Hitesh Shah, MS; N.D. Siddesh, MS; Harish Pai, MS; Stéphane Tercier, MD; Benjamin Joseph, MS, MCh. J Bone Joint Surg Am, 2013 Feb 20;95(4):354-361.
- **Effects of Non-Weight-Bearing on the Immature Femoral Head Following Ischemic Osteonecrosis: An Experimental Investigation in Immature Pigs.** Harry K.W. Kim, MD, MS, FRCSC; Olumide Aruwajoye, MS; Jeffrey Stetler; Alec Stall, MD. J Bone Joint Surg Am, 2012 Dec 19;94(24):2228-2237.
- **Microcrack Density and Nanomechanical Properties in the Subchondral Region of the Immature Piglet Femoral Head following Ischemic Osteonecrosis.** Aruwajoye OO, Patel MK, Allen MR, Burr DB, Aswath PB, Kim HKW. Bone 52:632-39, 2013.
- **Management of Legg-Calvé-Perthes Disease Using an A-Frame Orthosis and Hip Range of Motion: A 25-Year Experience.** Rich, Margaret M. MD, PhD; Schoenecker, Perry L. MD. Journal of Pediatric Orthopaedics: 33(2):112-119, Mar 2013.
- Let us know if you have LCPD related publications for our next issue.



To remove your name from our mailing list, please email Jamie Burgess at Jamie.Burgess@tsrh.org.

Questions or comments? E-mail us at Jamie.Burgess@tsrh.org or call 214-559-8569