

IPSG NEWSLETTER

Volume 1, Issue 3 September 11, 2013



No More Mushrooms!

Dear Members,

We are in the home stretch leading up to the second annual IPSG meeting! Please RSVP about your meeting attendance to Jamie (Jamie.burgess@tsrh.org) as soon as possible if you have not already. The meeting agenda is packed with important items on recent research developments, protocol and database discussions, and patient recruitment and enrollment.

Our study group website (www.perthesdisease.org) is up and running and has received many positive comments. You can also search for "perthes study group" to get to the website. Our goal is to provide educational resources on Perthes and to reach out to the families. In fact, we already had a patient family contact us through the website to learn more about Perthes disease. Please take a moment to share the IPSG site with your patients and your hospital. We greatly appreciate your feedback and news of our members to help improve and continually update the website.

We look forward to seeing you at the annual meeting. We are entering into the next phase of the study group and your participation is crucial to our success and continued progress.

Sincerely,

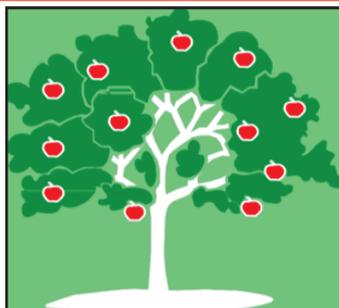
Harry Kim, IPSG Lead Organizer

Annual Meeting Action Items

Prior to the meeting, we need this information from you:

1. *Dietary requests and restrictions*
2. *Travel arrangements—please let Jamie know if you will need a shuttle to DFW airport after the meeting ends at noon on Saturday Oct 5th . We would also appreciate your flight info so that we know when you are arriving and need to depart.*
3. *The Warwick Melrose hotel is releasing unclaimed hotel rooms in our block on September 18th. Please make sure to contact them and request group reservations for the IPSG before that date if you intend to stay there. We will provide transportation between the hotel and TSRH during the meeting. The contact number for the Melrose is 1-214-521-5151 or 800-521-7172.*

Please contact Jamie with this information.



Numbers to date:

- **16 patients recruited!** (10 in 6-8 study and 6 in 8-11 study)
- **17 IRB approvals obtained!** 2 other IRB Approvals are waiting on Data Use Agreement approval.
- **12 centers approved for Perfusion MRI!**

IPSG Website News—Jay Janicki, subgroup leader

- The IPSG website can now be reached at www.perthesdisease.org or by searching for "perthes study group".
- You can help increase our visibility and patient outreach by asking your institution to link to our website. Many of your institutions already discuss your participation in the IPSG on your institutional website so please contact your local website administrator and request the addition of a link to the study group.
- Please share the website with your patients and their families. Patients can get involved in the group by submitting stories about their experiences and sharing the site with their pediatricians, family, and friends.
- We also have a [Facebook](#) page for the IPSG! Please "like" it and share with your patients.



Sites With IRB Approval:

Virginia Casey (OrthoCarolina)
Pablo Castañeda (Shriners Hospital for Children, Mexico City)
Paul Choi (Children's Hospital Los Angeles)
Nicholas Clarke (University of Southampton)
Skip Gilbert (The Children's Hospital of Alabama, Birmingham)
Benjamin Joseph (Kasturba Medical College)
Derek Kelly (Campbell Clinic Orthopedics, Memphis)
Harry Kim and Tony Herring (Texas Scottish Rite Hospital)
Jennifer Laine and Steve Sundberg (Gillette Children's)
Noelle Larson (Mayo Clinic)
Benjamin Martin (Children's National Medical Center, DC)
Ludwig Meiss (Orthopaedicum-Hamburg)
Scott Rosenfeld (Texas Children's Hospital)
Woody Sankar (Children's Hospital of Philadelphia)
Tim Schrader (Children's Healthcare of Atlanta)
Mihir Thacker (Nemours Delaware)
Roberto Guarniero (University of São Paulo School of Medicine)

Sites with Approval Pending Data Use Agreement Approval:

Norman Otsuka and David Feldman (Morgan Stanley Children's Hospital)
Eduardo Novais (Children's Colorado)

Dr. Herring and Dr. Kim review x-rays with Jay Boeing, a participant in the 30 year follow-up study of Dr Herring's original multicenter Perthes study.

Perfusion MRI

- Please send in a deidentified perfusion MRI if you have yet to do so: <http://www.tsrhc.org/forms/ShareFile/PerthesStudyGroup.html> If you have difficulty with uploading, please contact Jamie. *We have several centers with IRB approval but no approved perfusion MRI.*
- If you would like to bring in an MRI on a CD for review, Dr. Molly Dempsey will be available during the annual meeting to review MRIs and answer questions about the MRI protocol.



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 her at 214-559-8569