

No More Mushrooms!

Dear Members,

I would like to thank everyone who participated and contributed to another very productive annual meeting. This newsletter summarizes some of the items discussed. We began our discussion on organizing and setting up a study protocol for the post-collapse study. We also discussed several ongoing and new studies. Please read the updates below and feel free to contact respective individual listed with any questions and if you would like to get involved with these studies.

As you can see by our stats, perfusion MRI and IRB approvals and patient enrollment numbers continue to rise. It is essential that we continue to put our efforts on following the correct IPSG perfusion MRI protocol and enrolling all potential patients.

In upcoming weeks, we will make substantial updates to our webpage and Facebook by creating a Parent's section and regularly updating the content as well as frequently adding current news. These efforts will help increase our group visibility and awareness of Perthes in the community. It will also help us with patient enrollment. I would like to thank Eduardo Novais or stepping up to help organize and maintain the website.

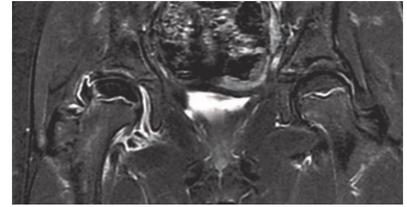
As many of you know, we have a new IPSG coordinator, Terri Beckwith. Please extend a warm welcome to Terri. Also, a big thank you goes to Jamie Burgess for all the hard work she has dedicated towards setting up the infrastructure of IPSG and coordinating last two annual meetings.

Finally, I would like to congratulate Josh Hyman, Hiroko Matsumoto, and the team of IPSG members who contributed to the modified Waldenstrom staging study. We just heard from JBJS that the paper will be accepted with minor revisions. The paper received one of the most positive reviews I have seen from JBJS in years!

Let's keep the momentum going and work together to make an impact on Perthes disease.

With warm regards,

Harry Kim, IPSG Chair



www.perthesdisease.org

Visits this Year: 4,294



Facebook Likes: 362

Enrollment

- 59 patients recruited!
- 3 New Sites with IRB Approval: Calgary, Kaiser Permanente & Shriners Salt Lake City
- 30 Sites Reproduced MRI Protocol
- Remember to enroll patients in PROMIS. Goal is to have 200 in each age group

IPSG ANNUAL MEETING RECAP



CURRENT STUDY PROTOCOL DISCUSSIONS

- MRI observation study: any patient with perfusion >50% head can be enrolled into this group.
- 6-8 group (Jennifer Laine): 29 enrolled but 26 are in the operative arm. We need more members to enroll non-op patients
- 8-11 group (John Tis): thigh girth and foot measurements are no longer required!
- For 8-11 group, 6 months non-weight bearing can be followed by gradual partial to full WB over next 6 months
- For >11 group, contact Eduardo to get surgical technique for drilling and arthrodiastasis
- Data share agreement (Matt Ferguson): updated version will be sent out soon to those centers that have not yet signed on.
- Perfusion MRI (Molly Dempsey and Terri Beckwith): need to make sure that the IPSG protocol is followed. Subtraction should be postcontrast minus precontrast scan and not the other way.

OTHER ONGOING AND FUTURE STUDIES

- PROMIS (Hiroko Matsumoto): currently enrolled 55 in Peds & 24 in Proxy; totaling 79. Need to reach 200 patients in each group. 10 centers are involved but we need more.
- MRI Estimation Study (Simon Thomas and Noelle Larson): preliminary results show good correlations between observers using the "eye balling" method.
- Transphyseal Neck & Head Tunneling (Nuno Lopez): discussed whether we should consider prospectively enrolling patients treated with this method.
- Femoral Head Shape Analysis (Kish Mulpuri): need other centers to contribute fine cut MRI and CT scans of healed Perthes patients for this study.
- Chronic synovitis in LCPD (Harry Kim); found elevated IL-6 in the synovial fluid of Perthes patients. Would like other centers to contribute normal and Perthes synovial fluid. Contact Terri Beckwith for protocols.

IPSG ADMINISTRATION

- Funding (Jay Janicki): we plan to submit 2 grants to POSNA this year and 1 grant to OREF next year.
- Membership Requirements (Kish Mulpuri and Harry Kim): some modifications have been made. Key point is that you need to enroll at least 1 patient per year to be consider an active member. See details in IPSG member section www.perthesdisease.org



POST COLLAPSE PROSPECTIVE STUDY PROGRESS

The post collapse prospective study is making progress in its details. Ben Martin and Jennifer Laine will be organizing this study. At the recent IPSG meeting, three possible study arms were discussed:

- **Observation group (symptomatic treatment only)**
- **Non-operative containment (Petrie cast and Bracing)**
- **Operative Containment (Femoral varus osteotomy or Shelf)**

Suggested Inclusion Criteria: stage IIB & IIIA, Unilateral,
Suggested Exclusion Criteria: Non-Perthes, IIIB or later

A bracing protocol is in the works as well as defining hinge abduction and which types of xrays are necessary for the study. Pre-treatment MRI will be optional.

PARENT SUPPORT GROUP

Something new at the meeting this year! Mallory Barth (mom of patient with Perthes) was our luncheon speaker. She presented a parent's perspective in dealing with Perthes and shared great ideas and suggestions on making our website more user friendly for parents. Based on Mallory's suggestions, we are currently developing a Parental Resource Tab to incorporate FAQ's and share information about supportive ideas and resources for parents. With these upgrades and our increasing Facebook traffic, more patients and parents, like Mallory, will be actively involved with IPSG. Please let your parents know about our IPSG Website and Facebook Community.

IPSG WEBSITE AND FACEBOOK

Eduardo Novais of Children's Colorado, Tim Shrader of CHOA Atlanta, Lindsay Arnott of Nationwide Children's, and Terri Beckwith with Amanda Moualeu of TSRH, have graciously volunteered to help organize and maintain the IPSG website and Facebook Community. We are in the process of adding more content to increase traffic and awareness of IPSG. Daily updates are being made regarding new members, interviews, up to date literature, events and photos. **BE ON THE LOOK OUT** for a biosketch template in the near future for our webpage. We would like to use this template to highlight an IPSG member each month.