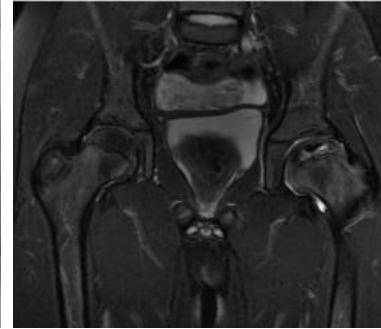


International Perthes Study Group

IPSG Newsletter

Volume 5, Issue 1 • February 2017

No More Mushrooms!



Dear Members,

I hope 2017 is turning out to be a fun and productive year for everyone. I would like to welcome three new members to IPSG –Jianping Yang MD (China), David Godfried MD (New York), and Susan Novotny PhD (Minnesota). I would also like to welcome back Pablo Castaneda, M.D., who has relocated from Mexico City to New York City.

I am happy to report that IPSG has achieved some new milestones since our last newsletter. We now have 206 patients enrolled into our REDCap database and have over 1600 Facebook likes. Our Google search ranking for the term “Perthes disease” has also moved up to the 3rd page. I am also excited to report that our IRB (Scottish Rite Hospital) has approved the expansion of our prospective studies to include patients <6 years of age and patients of all ages (1-18 years old) who present at a late stage of Perthes (modified Waldenstrom 2b or 3b). Once our REDCap database is updated with new data dictionary and data points we will start the patient enrollment. The expansion of the scope of our prospective studies to include all ages and stages will allow us to do more comprehensive studies on Perthes. To get everyone on board with the expanded study protocol, we will be sending a copy of Scottish Rite Hospital’s IRB protocol soon for your own IRB modification and submission. Please note that for patients presenting in a late stage of Perthes, AP pelvis X-ray with maximum abduction of the legs is required for patient enrollment BUT perfusion MRI is not required.

John Tis, Becca, and others are currently organizing the X-ray Validation Study that we discussed at the last annual meeting. Becca has now compiled X-rays of 40 patients with 2 year follow up. These X-rays will be used to validate lateral pillar classification, epiphyseal extrusion index, and serial modified Waldenstrom staging. You will soon hear from John regarding the study.

Finally, please mark your calendars for the upcoming IPSG annual meeting in Dallas which will be from October 6th-7th. If you have any new ideas for the meeting, new research projects, or Perthes talk you would like to give or hear about please let us know by emailing IPSG@tsrh.org.

I would like to thank you all for your contribution to patient enrollment, to various aspects of IPSG endeavors, and to your enthusiasm to keep our momentum going! My special thanks to the members of the IPSG Coordinating Committee, Becca, Terri, and Maggie. I am very proud of our group and the progress we are making.

Warm Regards,
Harry

New Members to IPSG



Susan Novotny, Ph.D.

Gillete Children's — St. Paul, Minnesota

Susan Novotny, Ph.D., is from Gillete Children's in St. Paul Minnesota. She is our first scientific member and is primarily working to develop the new IPSG REDCap database. She is working on both design, usability and content.

Jianping Yang, M.D.

Tianjin First Central Hospital — Tianjin, China

Orthopedic surgeon

Dr. Yang is IPSG's very first member from China. He has received his IRB approval and is ready to enroll patients.



David Godfried, M.D.

NYU Langone Medical Center— New York City, New York

Clinical Associate Professor, Department of Orthopaedic Surgery

Clinical Associate Professor, Department of Pediatrics

Director, Center for Children at NYUHC-HJD

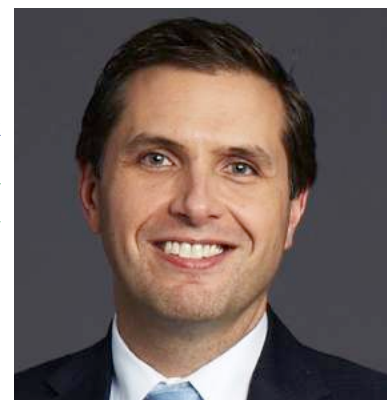
Dr. Gofried has IRB approval and is ready to enroll patients.

Pablo Castaneda, M.D.

NYU Langone Medical Center— New York City, New York

Division Chief - Pediatric Orthopaedic Surgery

Previously, Dr. Castaneda was a member representing Shriner's Hospital in Mexico. Now that he is at NYU Langone Medical Center, he has renewed his membership with IPSG.



Enrollment Update

<u>6-8 Cohort</u>	<u>121</u>	<u>8-11 Cohort</u>	<u>76</u>	<u>Over 11 Cohort</u>	<u>9</u>
Hitesh Shaw	18	Hitesh Shaw	15	Harry Kim	3
Harry Kim	12	Harry Kim	11	Derek Kelly	1
Won Joon Yoo	10	Woody Sankar	9	Eduardo Novais	1
Scott Rosenfeld	9	Woo Joon Yoo	7	Scott Rosenfeld	1
Woody Sankar	8	Ben Martin	5	Kevin Klingele	1
Simon Thomas	6	Meiss & Benke	3	Virginia Casey	1
Ben Joseph	5	Vedant Kulkarni	3	Woo Joon Yoo	1
Derek Kelly	5	Steve Sundberg	2		
Steve Sundberg	5	Derek Kelly	2		
Jennifer Laine	4	Jay Janicki	2		
Ben Martin	4	Scott Rosenfeld	2		
Ferri de Barros	4	Chuck Mehlman	2		
Paul Choi	4	Jeff Kessler	2		
Meiss & Benke	4	Kevin Klingele	2		
John Tis	3	Virginia Casey	2		
Jay Janicki	2	Jennifer Laine	1		
Ralf Stuecker	2	Benjamin Shore	1		
Kevin Walker	2	John Tis	1		
Kevin Klingele	2	Phil Mack	1		
Tim Shrader	2	Walter Truong	1		
Junichi Tamai	1	Salil Upasani	1		
Tony Herring	1	Tony Herring	1		
Eduardo Novais	1				
Benjamin Shore	1				
Virginia Casey	1				
Salil Upasani	1				
Guarniero & Moreno	1				
Walter Truong	1				
Benjamin Novak	1				
Deborah Quanbeck	1				

TOTAL
Patients

206

MARK YOUR CALENDARS

The date for the 2017 IPSPG Annual Meeting has been set!

October 6th-7th

Texas Scottish Rite Hospital for Children - Dallas, TX

October 5th, the IPSPG coordinating committee will meet before the start of the annual meeting.

Online Registration this year!

Please look for an email from IPSPG@tsrh.org toward the end of April that will include a link to the RSVP online page.

Members will be able to RSVP, record food allergies and hotel information will be provided so that each member is able to reserve their hotel reservation for their stay in Dallas.

We will start the RSVP process early this year so that we can plan accordingly for room space and dietary needs.

What's new with IPSG

FACEBOOK



1,613  108 followers since November

What do our followers like?



- Donations
- Patients with their doctors
- Patient stories

All videos from the 2016 annual meeting are now complete. We will be posting them to Facebook, and then to the website throughout the year. Thank you to all who participated!

What's new?

X-ray Validation Study

Surgeons will independently review x-rays of 40 Perthes patients participating in IPSG who have a minimum of two years radiographic follow-up. Specific measures to be validated include the modified Waldenstrom classification, lateral pillar classification and extrusion index. This study is intended to assess the inter- and of surgeons performing these radiographic measurements in each center.

REDCap Database Update

The REDCap database will shut down in March to update our database infrastructure and to add new data points. All patient data should be updated by the end of February. The data migration will start in March and the new database will be opened for use by the end of March/early April. Please let Becca Nelson know who the active users are at your sites. No individual will be added to the database or given rights unless they inform Becca that they need it.

Expansion of IPSG Studies

We have now implemented the <6 and late stage cohorts, resulting in an expansion from the current three early stage cohorts. Patient enrollment can now include patient aged 1-18, at time of diagnosis presenting at early or late Waldenstrom stages (I-III).

Before: 6-8 cohort, presenting in Waldenstrom stages Ia, Ib or IIa
8-11 cohort, presenting in Waldenstrom stages Ia, Ib or IIa
>11 cohorts, presenting in Waldenstrom stages Ia, Ib or IIa

Current, as of Feb. 2017:

1-6 cohorts, presenting in Waldenstrom stages I, II or III
6-8 cohorts, presenting in Waldenstrom stages I, II or III
8-11 cohorts, presenting in Waldenstrom stages I, II or III
>11 cohorts, presenting in Waldenstrom stages I, II or III

Our current cohorts will stay the same -- we are only adding the 1-6 and late stage cohorts, but anticipate stratifying these by age and stage to remain consistent with our set up. Scottish Rite Hospital has acquired IRB approval and will send out the approval letter, protocol, SOPs and data collection documents as soon as possible. Please anticipate updating your study protocol shortly after you receive these documents, in order to obtain local IRB approval.

OUR MISSION

To advance knowledge of Perthes disease and to disseminate objective, evidence-based information to the patients, their families, and to the medical community.



A special thanks to the following:

