

Primary Immune Deficiency Treatment Consortium



Year 8 Recap from Dr. Cowan

As we welcome the next funding year I want to thank everyone who has worked towards our progress this past year. As you all know, we are currently prepping for the U54 grant renewal, and I am pleased to report we have made significant progress on our current protocols and are currently developing a number of new protocols!

Our 6901 protocol working team is close to publishing a paper on the first 100 patients in this study in *Blood*! Not far behind, our 6902 team soon will be submitting a manuscript on strata A and B and is beginning the data clean-up for a report on a large cohort of patients with ADA-SCID.

We have begun the initial analysis for our 6903 (CGD) and 6904 (WAS) protocols in order to write our first manuscripts. I would like to thank each of the centers that worked hard to meet the deadlines in order to contribute patients to these cohorts.

In addition to the prospective multicenter 6905 protocol on low/moderate exposure busulfan-based conditioning for newly diagnosed patients with SCID lead by **Sung-Yun Pai** and **Mike Pulsipher's** and recently funded by NIAID, we also have a team in place led by **Troy Torgerson**, **Alice Chan** and **Jennifer Leiding** to put together the 6906 Primary Immune Regulatory Disorders protocol.

These protocols will be followed by the implementation of 6907 (SCID), which will combine 6901 and 6902 and be led by **Chris Dvorak** and **Elie Haddad**. Please let us know if you are interested in joining any of these new protocol teams; we would be happy to have you!

We still have quite a bit of work to prepare for the grant renewal, and I would like to remind everyone that closing the 6903 and 6904 retrospective studies will be crucial to this. Our final deadline for these studies was June 30th, 2017. We did not meet our goal of completing data entry on all retrospective patients so I urge centers to take this a priority to complete these as soon as possible. Thank you for your continued hard work to meet this goal!

Finally, I wish to thank everyone who attended the Scientific Workshop and education day this past May at the NIH. It was a very successful meeting and I extend a huge thanks to Linda Griffith for hosting. Next year's PIDTC Scientific Workshop will be hosted May 9th-11th, 2018 (Education Day: May 8th-9th, 2018) by **Jen Heimall**, **Kate Sullivan**, and **Nancy Bunin** from The Children's Hospital of Philadelphia.

Once again, thanks for a successful year; I look forward to even more exciting accomplishments in the coming grant year!!

-Mort

IN THIS ISSUE

[Patient Advocacy Group Update](#)
IDF National Conference 2017 Recap

Page 2

[PIDTC 2017 Scientific Workshop](#)
Recap on Workshop and Education Day

Page 3

[Current Enrollments and Goals](#)
XS, retrospective, prospective progress

Page 3

[6901 Prospective SCID Update](#)
First 100 Manuscript submitted to Blood

Page 3

[PIDTC Patient Highlight](#)
Meet the SCID families that attended the IDF conference!

Page 3

[6902 Retrospective/ XS SCID Update](#)
Need to recruit cross-sectional patients!

Page 4

[6903 CGD & 6904 WAS Update](#)
Need to complete the retrospective data sets!

Page 4

[6905 & 6906 Intros & Updates](#)
Our newest protocols in development!

Page 4

[RDCRN DMCC & cIRB Updates](#)
New electronic Delegation log

Page 6

[Announcements](#)

Page 6

[Deadlines](#)

Page 10

Patient Enrolment: Aug 31st, 2017
Invoice Submission: Oct 15th, 2017

PAG Update

Many of you are aware that we have a contact registry available on our website that allows patients to sign up and ask more about participating on our studies. We have made a lot of progress in connecting PID patients across the country with our studies thanks to the incredible help of our Patient Advocacy Groups with special thanks to the **IDF** and **Heather Smith** with SCID Angels! We had the chance to meet a lot of these families at the 2017 IDF National Conference this past June in Anaheim, so please be sure to check out the recap below!

Following more than 37 years of passionate leadership, Immune Deficiency Foundation (IDF) President & Founder **Marcia Boyle** recently announced her plans to retire. Marcia co-founded IDF in 1980 after her son's diagnosis with a primary immunodeficiency disease (PI), and has since worked tirelessly to provide educational materials and advocacy for people with PI like her son John. Marcia plans to continue to lend her time and talents as a volunteer and member of the foundation's Board of Trustees. The PIDTC would like to thank Marcia for the legacy she has established in the PI community and the tenacious, passionate, and impactful support she has provided to the patients she has served for nearly 4 decades!



Marcia Boyle

We are also deeply saddened to announce the passing of **Mary Hurley**, the founder of The Chronic Granulomatous Disease Foundation, after a long battle with cancer. Mary and her husband Alan created the CGD Association in 1982 after their two sons, Erik and Stephen, were born with CGD. Their mission was to provide emotional support to other patients and families and to educate physicians and other organizations of the diagnosis and treatment for CGD. We would like to offer our deepest condolences to the Hurley Family, and thank them for the amazing contributions Mary and the CGD Association have made to the CGD Community. Mary will be truly missed by all those who had the privilege of knowing her.



Mary Hurley and her son at the IDF retreat in 2014



Chronic Granulomatous Disease Association



Immune Deficiency Foundation 2017 National Conference Recap

We would like to congratulate **Marcia Boyle** and the IDF on a successful IDF National Conference this year in Anaheim! The PIDTC hosted a booth at the exhibition hall and spoke at the Special SCID Symposium Session. We also had a number of our PIs present at the Special Symposiums for SCID, CGD and WAS where we got to hear many of our patients and their families tell their incredible stories. These symposiums had an amazing turnout and we would like to congratulate **Heather Smith** and **Amy Walsh** on leading an incredible SCID Symposium! Below are some pictures from the event!



Top left: Some of the SCID families posed during the SCID Symposium session! **Top Right:** There were many fun activities for all the kids in attendance at the conference exhibition hall! **Bottom Left:** PIDTC PMs, **Megan Murnane** and **Tara Bani** at the PIDTC Booth! **Bottom Right:** Families at the WAS Symposium listening intently during speaker presentations!

2017 Annual PIDTC Scientific Workshop and Education Day Recap

HOSTED BY LINDA GRIFFITH AT THE NIH IN BETHESDA, MD

We would like to extend a special thanks to Linda Griffith and the 2017 workshop committee:



Linda Griffith
Chair



Mort Cowan
Co-Chair



Elie Haddad
Education Day Chair

As well as all of our PIDTC leadership:

Mort Cowan, Jennifer Puck, Luigi Notarangelo, Elie Haddad, Chris Dvorak, Sung-Yun Pai, Marcia Boyle, Lauri Burroughs, Elizabeth Kang, Elizabeth Dunn, Megan Murnane, and Tara Bani

This year's annual Scientific Workshop was held in Bethesda at the NIH Campus. We had over 125 attendees at the workshop and about 36 Education Day Participants. Everyone in attendance posed on the stairs of NIH building 35 (pictured below)! We would also like to thank all of our speakers!

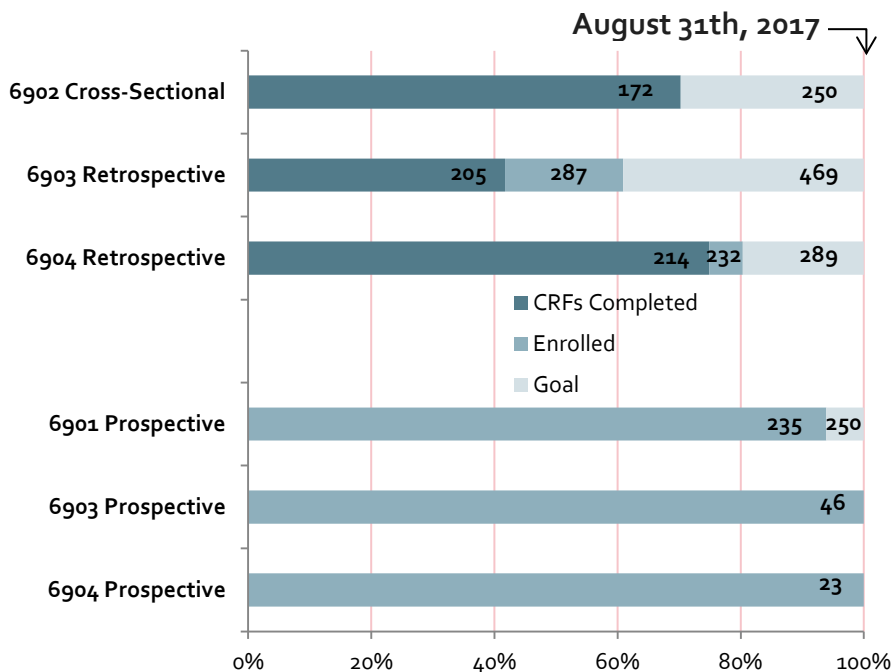
During the 3 day event, we heard some great talks from: Linda Griffith, Rashmi Gopal-Srivastava, Mort Cowan, Jim McNamara, Brent Logan, Chris Dvorak, Jennifer Heimall, Elie Haddad, Caroline Kuo, Jeff Krischer, Brian Sorrentino, Harry Malech, Don Kohn, Sung-Yun Pai, Julie Segre, Andrew Gennery, Michael Pulsipher, Lauri Burroughs, Gulbu Uzel, Steve Holland, David Rawlings, Catherine Biggs, Marcia Boyle, Christopher Scalchunes, Heather Smith, Suhag Parikh, Sumathi Iyengar, William Shearer, Craig Platt, Monica Thakar; presented by Larisa Broglie, Rebecca Marsh, Michael Jordan, Despina Moshous, Elizabeth Kang, Emilia Falcone, Marcel van den Brink, Jennifer Leiding, Troy Torgerson, Jeff Cohen, Josh Milner and Alice Chan.

We would further like to acknowledge our top abstract winners who gave presentations at the workshop: Caroline Kuo, Michael Keller, Craig Platt and Monica Thakar; presented by Larisa Broglie.

The next PIDTC Scientific Workshop will be held May 09-11, 2018 in Philadelphia with Education day taking place May 08-09, 2018. See you next year!



Enrollment and Accrual Progress Update



For any inquiries regarding PIDTC patient accrual or DMCC related inquiries please contact the DMCC project managers, Amoy Fraser at Amoy.fraser@epi.usf.edu



6901 Prospective SCID Update

Our First 100 patient's manuscript has been submitted to *Blood* and our protocol team and publications committee are currently working on addressing revisions. We would like to thank **Dr. Chris Dvorak** of UCSF, **Dr. Jennifer Heiwall** of CHOP, and our statistician, **Dr. Brent Logan** of the Medical College of Wisconsin for all of their hard work on the manuscript and to all the centers, including the physicians and CRA's who contributed patients and completed the CRFs for the first 100!

While the 6901 V4.0 protocol revisions included the addition of T cell exhaustion studies, we are currently not accepting sample while preparing for the study. We anticipate this portion of the study to commence in the Fall of 2017 at which time the PIDTC project managers will notify you.

We would also like to remind centers that the 6901 V4.0 has been revised to now include two additional time points: 60 months and 96 months. This will require patients to be re-consented prior to data and sample collection. Please be conscious of this as patients come in for their next visit.

Please contact **Tara Bani** at Tara.Bani@ucsf.edu for 6901 inquiries.

PIDTC Patient Highlight

All of the SCID Patients and Families that bravely shared their stories during the Special SCID Symposium



There were over 80 people in attendance at the Special SCID Symposium at the IDF Conference this year and countless stories

The PIDTC wants to hear about your patients! If you would like one of your patients featured in next quarter's issue, Please send a photo and a brief blurb to Vy.Nguyen1@ucsf.edu

6902 Retrospective and Cross-sectional SCID Update

We have been undergoing an extensive clean-up of the 6902 retrospective data sets. The near completion of this massive feat and the near completion of the manuscript is largely thanks to **Brent Logan, Elie Haddad, and Tara Bani**, and the rest of the **6902 protocol team**.

URGENT REMINDER: Sites should be recruiting for the 6902 Cross Sectional Study!

We cannot emphasize enough the importance of recruiting 6902 patients in for a cross sectional visit and we ask that all centers make a large push to do so. Our goal is to bring in an additional 78 patients for a cross-sectional visit by the end of August. Sites will receive a \$750 reimbursement per patient enrolled with CRF completion! **We would like to extend a special thank you to the Jeffrey Modell Foundation for providing the funding that allows us to make these reimbursements!**

It is now possible for centers to do a cross sectional visit over the phone for patients that have moved away using a revised consent and interview script. Please let us know about your experiences with phone interviews.

Project manager, Vy Nguyen, will be checking in regularly about your centers progress in bringing in each of the remaining 6902 patients at your center for a cross sectional visit.

Again, we would like to remind centers to be sending the optional study samples for the cross sectional visits, especially samples for the **T cell exhaustion study** to the Decaluwe lab, the **CD34 Progenitor Cell Study** to the Malech lab, and the **T Cell Study** to the O'Reilly lab.

62% of goal

172

6902 Cross-sectional visits to reach our goal of **250** total visits by **August 31st, 2017**

6905: Prospective Randomized Busulfan Trial for IL2RG, JAK3 and RAG1/2 SCID

Dr. Sung-Yun Pai and Dr. Mike Pulsipher have received very good news on their grant submission to support a randomized trial of low versus moderate dose busulfan for transplant of SCID due to defects in IL2RG, JAK3, RAG1/RAG2. Reviewers have given it an impact score of 20 and percentile score of 5.0. The study currently has provisional approval and is projected to begin in the first quarter of 2018. A final funding decision is expected soon – the study would be funded for 7 years. The study will be open to all PIDTC and PBMTTC centers. The study will operate under a central IRB at CHLA.

6903 Chronic Granulomatous Disease & 6904 Wiskott - Aldrich syndrome Update

With the conclusion of our FINAL June 30th retrospective deadline, we have completed **205 CGD** retrospective patients and **214 WAS** retrospective patients. We however, did not meet our goal for the year and we cannot emphasize the importance of completing data on all of our retrospective patients.

Our protocol teams have already begun an initial analysis on each of the studies; both 6903 & 6904 focusing on patients transplanted 2005. If you have contributed to these cohorts, please work with us as you receive queries from our project manager, Vy Nguyen, while these data sets are cleaned up.

Our project manager, Vy Nguyen, will be contacting each center regarding outstanding patients that need to be completed for these studies as a number of centers are behind. Please contact her for any questions regarding the expected numbers of CGD and WAS retro patients for your center.

44% of goal

205

6903 CGD retrospective patients enrolled and completed of **469** total patients by **August 31st, 2017**

53% of goal

214

6904 WAS retrospective patients enrolled and completed of **289** total patients by **August 31st, 2017**

Please contact **Tara Bani** at Tara.Bani@ucsf.edu for any 6902 inquiries and **Vy Nguyen** at Vy.Nguyen1@ucsf.edu for 6903 and 6904 inquiries.

6906 PIRD (Primary Immune Regulatory Disorders)

PIRD, previously known as IDD (Immune Dysregulatory Disorders), focuses on evaluating the natural history, quality of life, therapeutic responsiveness including HSCT outcomes, and the molecular etiology of disease in disorders of dysregulated immunity. This group of diseases is characterized by having clinical manifestations of autoimmunity, autoinflammation, non-malignant lymphoproliferation, and immunodeficiency. Examples of these diseases include IPEX, CTLA haploinsufficiency, STAT1 gain-of-function, and STAT3 gain of function. This study will have both a retrospective and prospective component to help better define this group of disorders.

If you're interested in getting involved or for more information, please contact:

PI: **Troy Torgerson** (Troy.Torgerson@seattlechildrens.org)
Co-I: **Alice Chan** (Alice.Chan1@ucsf.edu)
Co-I: **Jennifer Leiding** (JLeiding@health.usf.edu)
Project Manager: **Tara Bani** (Tara.Bani@ucsf.edu)

RDCRN/DMCC and Central IRB Update

BY AMOY FRASER

The DMCC recently introduced the electronic site delegation log! This is exciting for all of the coordinators and PIDTC project management team and will make the regulatory process a lot more seamless! Centers should be working on transitioning to the electronic SDL!

You can contact Amoy at Amoy.Fraser@epi.usf.edu



Current progress: The UCSF IRB is serving as the PIDTC central IRB for protocols 6901, 6902, 6903 and 6904. Thus far, 17 institutions have signed a reliance agreement to cede review of these studies to the UCSF IRB; nine of these sites have successfully obtained central IRB approval.

Future steps: PIDTC, the UCSF IRB and the OneIRB Coordinating Center continue to work with sites and institutions on central IRB implementation. If your site is continuing to work on local context review requirements for central IRB submission, or if your institution has not yet signed the reliance agreement or originally declined, but is now interested in moving forward, please contact Tara and OneIRB with any questions for concerns or for information on how to move forward.

Importantly, please remember to keep your local IRB application active until you receive a central IRB approval letter for your site. Even if your institution has signed the reliance agreement and your site is in the process of completing local context review documents required for central IRB submission, it is imperative that you continue to submit your continuing review applications to your local IRB to avoid a lapse in IRB approval and allow for a smooth transition to the central IRB. Please contact Tara and OneIRB if you have any questions or concerns regarding this information.

Individual Study Updates & Reminders:

- **PIDTC 6901:** IRB approval expiration date: **09-May-18**
 - Study-wide protocol amendment (for Version 4) approved on 25-Apr-17.
- **PIDTC 6902:** IRB approval expiration date: **20-Nov-17**
 - The study-wide protocol amendment (for Version 4) approved on 28-Apr-17.
- **PIDTC 6903:** IRB approval expiration date: **13-Jun-18**
- **PIDTC 6904:** IRB approval expiration date: **23-Mar-18**

Announcements



Elizabeth Dunn

Elizabeth Dunn has moved from Senior Project Manager to Strategic Advisor for PIDTC Studies

After 26 years working at UCSF under Dr. Cowan and 8 of those years as PIDTC's Senior Project Manager, Elizabeth has moved into a new role - Strategic Advisor for PIDTC Studies. She will continue to work closely with Dr. Cowan, Dr. Puck and other study team members, focusing on the PIDTC U54 grant renewal. She will be monitoring the progress of each of the current protocols as well as new protocols being developed for the U54 submission which is due in about a year.

We would like to thank Elizabeth for all her great work and look forward to having her continued knowledge and expertise in her new advisory role.

A few words from Elizabeth: *"I am so very grateful for the many years I have worked at UCSF and for the opportunity to work with so many gifted and dedicated people, and especially for my wonderful boss, Dr. Cowan. I am truly looking forward to continued participation in the PIDTC project and mission to serve patients affected by a primary immune deficiency and their families."*

Announcements Continued

Congratulations to Tara Bani on becoming our new PIDTC Lead Project Manager!

After 2 years of being one of our Assistant Project Managers, we are excited to have Tara as our new Lead Project Manager. She will continue working on the implementation of the central IRB and managing the 6901 and 6902 studies, along with other protocols, the overall study management and oversight of CRFs, PIDTC policies, SOPs and lab procedures, among other tasks.

A message from Tara:

"I feel so privileged to be given the opportunity to take on the Senior Project Manager role for the PIDTC. I want to thank all of you for your dedication and for making this such an inspiring and gratifying role. I look forward to seeing the PIDTC continue to grow and to witness such a strong collaboration. I would like to especially thank Elizabeth Dunn for being such an incredible mentor and for all her support."



Tara Bani

Introducing Our Newest PIDTC Project Manager: Vy Nguyen!



Vy Nguyen

Please welcome our newest PIDTC project manager Vy Nguyen, who will be taking over for Megan Murnane later this month. Vy will be involved in all regulatory management, the 6903 & 6904 studies, as well as other protocol teams, maintaining our continued collaboration with our Patient Advocacy Groups and much more.

Vy is coming to us from Toronto, Canada. She has extensive clinical research experience having worked several years at Sunnybrook Health Sciences Centre and St. Michael's Hospital managing a number of multicenter protocols. We are confident she will make a wonderful addition to the PIDTC team and are thrilled to have her.

From Vy: *"It is with much appreciation and excitement that I am joining the PIDTC team. I look forward to contributing to PIDTC's growth and success. I would like to give a special thanks to Megan for her guidance and support during this transition period. She has done wonderful work and I hope to be able to continue on with the same poise and grace. I am absolutely delighted and honoured to working with everyone!"*

PIDTC Annual Workshop!

The **2018 Annual PIDTC Scientific Workshop** will take place:
May 9-11th, 2018
 at the Children's Hospital of Philadelphia in Philadelphia, PA

Education Day will held be on:
May 8th, 2018



Anti C-Kit Clinical Trial for SCID patients who never gained B cells

This Phase I study is a single arm, open label, dose escalation trial being conducted at 2 centers: UCSF Benioff Children's Hospital and Lucile Packard Children's Hospital at Stanford. The study objective is to evaluate the safety and tolerability of tandemly-purified allogeneic CD34⁺CD90⁺ human stem cells (HSC) in patients with Severe Combined Immune Deficiencies (SCID) conditioned for transplantation with AMG 191, a monoclonal antibody that targets human CD117. It will enroll SCID patients sequentially in three groups based on age: Groups A and B will enroll patients ≥ 12 and from > 2 to ≤ 12 years of age respectively, who have previously undergone an allogeneic human stem cell transplants (HCT) but have low-level donor engraftment and inadequate T and/or B cell function. Group C will enroll patients > 3 months of age with newly diagnosed SCID. Group B will start enrollment after the first dose cohort of Group A has been completed. Group C will start enrollment after the first dose cohort of Group B has been completed.

For questions regarding the trial please contact **Dr. Mort Cowan** (Mort.Cowan@ucsf.edu, 415-476-2659) or **Dr. Chris Dvorak** (Chris.Dvorak@ucsf.edu, 415-476-2188) at UCSF, and **Dr. Rajni Agarwal** (rajnia@stanford.edu, 650-724-7173) at Stanford

Gene Transfer for SCID-X1 using a self-inactivating (SIN) gammaretroviral vector

The trial is currently open and enrolling and performed as a collaboration among U.S. sites at Children's Hospital Boston, Cincinnati Children's, and Mattel Children's Hospital (UCLA), and the Great Ormond Street Hospital in London.

For eligibility or more information about the study, please contact:

Sponsor - David A. Williams, M.D. (david.williams2@childrens.harvard.edu)

Boston – Sung-Yun Pai, M.D. (Sung-Yun.Pai@childrens.harvard.edu)

Cincinnati – Rebecca Marsh, M.D. (Rebecca.Marsh@cchmc.org)

Los Angeles – Donald Kohn, M.D. (dkohn1@mednet.ucla.edu)

Clinical Trial for X-Linked Severe Combined Immunodeficiency in Newly Diagnosed Infants

A Pilot Feasibility Study of Gene Transfer for X-Linked Severe Combined Immunodeficiency in Newly Diagnosed Infants Using a Self-Inactivating Lentiviral Vector to Transduce Autologous CD34⁺ Hematopoietic Cells. This trial is currently enrolling at St. Jude Children's Research Hospital in Memphis Tennessee and future enrolling sites include Seattle Children's Hospital/Fred Hutchinson Cancer Research Institute and University of California, San Francisco.

For eligibility or more information about the study, please contact **Dr. Brian Sorrentino** at ((901) 595-2727, Brian.Sorrentino@stjude.org) or **Dr. Ewelina Mamcarz** ((901) 595-8343, Ewelina.Mamcarz@stjude.org)

A Phase I/II Open Label Study of Gene Transfer (Lentiviral vector transduced CD34+ cells) in Patients with CGD

Gene therapy for patients with the Chronic Granulomatous Disease (CGD) is now available at University of California, Los Angeles, Boston Children's Hospital, and the National Institutes of Health. This is a trial of gene transfer using a safety-improved, third generation self-inactivating lentiviral vector to transduce CD34⁺ selected hematopoietic stem cells. Genetically modified cells are infused after busulfan preparative conditioning. This trial will be conducted under an FDA Investigative New Drug Application and will be overseen by the NHLBI-appointed Data Safety Monitoring Board. The costs of research aspects of the protocol will be provided for patients treated on the trial by the California Institute of Regenerative Medicine (CIRM) and the Gene Therapy Resource Program, NHLBI and NIH.

Contact Information:

University of California, Los Angeles: Donald B. Kohn, M.D. (dkohn@mednet.ucla.edu) or Caroline Kuo M.D. (ckuo@mednet.ucla.edu)

Boston Children's Hospital: David A. Williams, M.D. (David.Williams2@childrens.harvard.edu) or Sung Yun Pai, M.D. (Sung-Yun.Pai@childrens.harvard.edu)

National Institutes of Health: Elizabeth Kang, M.D. (ekang@niaid.nih.gov) or Harry Malech, M.D. (hmalech@nih.gov)

A Phase II/III Trial of X₄P-001 with WHIM Syndrome (X₄P-001-MKKA)

Clinical trial using an oral CXCR₄ antagonist for the treatment of WHIM (Warts, Hypogammaglobulinemia, Infections and Myelokathexis) sponsored by X₄ Pharmaceuticals is currently recruiting patients who may be eligible for enrolment or would like to genetically test for WHIM syndrome. Many of these patients have chronic neutropenia and may have been identified as PID patient without the genetic confirmation of the CXCR₄ mutation.

Contact Information:

Please contact X₄ information at patientinfo@x4pharma.com or visit the clinical trial information page at X₄ WHIM Study

Heterozygous FOXP1 Patients

Dr. Louise Markert and Grace Padron are working together to describe a group of patients picked up by newborn screening who were found to have mutation(s) in Foxp1. They plan to publish a manuscript on the findings in **Foxp1 deficient patients picked up since 2014**. There are currently a total of 20 heterozygous subjects. The main focus of this report will be the high rate of Foxp1 mutations picked up by newborn screening; the difference in immune findings based on the location of the mutations (5' more serious); and How long one should wait before determining that the T cells will or will not increase.

For more information, please contact Louise Markert at m.markert@duke.edu

Pediatric PID BMT Caregiver

This study is currently recruiting caregivers of children with PID during BMT to take a survey to understand how to enhance caregiver well-being and resilience. This anonymous and voluntary survey will take about 15-20 minutes to complete and can be discontinued at any time. At this time, we are limiting the survey to **English-speaking families in the United States** and request that only one survey be submitted per family. The results from this survey will be used to identify potential organizational-level areas of improvement to enhance psychosocial support for family members during this difficult period.

For more information about the study:

<http://integration.ucsf.edu/caregiver-psychosocial-support-during-pediatric-medical-trauma>

To complete the survey, please go to the following link:

<https://is.gd/pediatricPIDBMTcaregiverstudy>

Contact Information:

Christina Mangurian, MD (Christina.Mangurian@ucsf.edu), Mort Cowan, MD (Mort.Cowan@ucsf.edu), or Jennie Yoo (Jennie.Yoo@ucsf.edu)

****The PIDTC does not necessarily endorse these studies, but provides this information to our members as a courtesy.**

If you are a PID patient and would like to participate on a PIDTC Study...



Join the RDCRN PIDTC Contact Registry!

The Contact Registry is a way for patients with primary immune deficiency and their family members to learn about PIDTC research studies and find out if they may be eligible to participate on one of our studies. Registration is completely voluntary and you may choose to withdraw at any time. There is no cost to

join the Contact Registry.

Follow the link to join today:

[Tinyurl.com/PIDTCregistry](https://tinyurl.com/PIDTCregistry)

Deadlines

Year 8 Patient Enrollment
All patients need to be enrolled by this deadline to be reimbursed by October 15th, 2017

August 31st, 2017

Patient Enrolment Deadline: August 31th, 2017

Invoice Submission Deadline: October 15th, 2017

January 2017	February 2017	March 2017	April 2017	May 2017	June 2017	July 2017	August 2017	September 2017	October 2017	November 2017	December 2017
--------------	---------------	------------	------------	----------	-----------	-----------	-------------	----------------	--------------	---------------	---------------

Year 8 Invoice Submission Deadline
All Retrospective 6903/6904
CRFs must be completed and invoice submitted for timely reimbursement

October 15th, 2017



PIDTC Newsletter

For questions about PIDTC Newsletter, please contact:

Vy Nguyen

PIDTC Project Manager

Vy.Nguyen1@ucsf.edu

(415) 476-3837

Brought to you by Megan Murnane, Vy Nguyen and the PIDTC Management Team