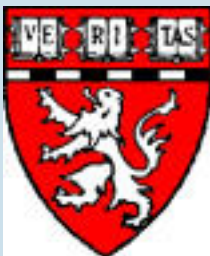


# Genetic Study of IC/PBS/CPPS Newsletter

April 2011, Volume 3

## Don't forget to check out...

- Find us on the web!
- [www.chb-genomics.org](http://www.chb-genomics.org)
- Click on "Interstitial Cystitis (IC)"
- Tell us what you want to hear about?
- See Reply Card on reverse!



## Study Enrollment Sky Rockets!

The Children's Hospital, Boston Genetics Study on Interstitial Cystitis/Painful Bladder Syndrome/Chronic Pelvic Pain Syndrome (IC/PBS/CPPS) recently partnered with the Interstitial Cystitis-Network (ICN, [www.ic-network.com](http://www.ic-network.com)) to help raise awareness for our research study.

In August of 2010, the ICN e-blasted information about our genetics study to its online members. We, the researchers at Children's Hospital Boston, were so excited by the fantastic response. The day following the e-blast, we received 600 responses by email alone, and by the end of the first week our contacts tallied over 800 between calls and emails. Thank you so much to the IC/PBS/CPPS community for your overwhelming support!

The enrollment team for the Genetics Study on IC/PBS/CPPS is made up of our study coordinator/genetic counselor and our genetic intern. The two worked tirelessly to contact each individual that requested information.

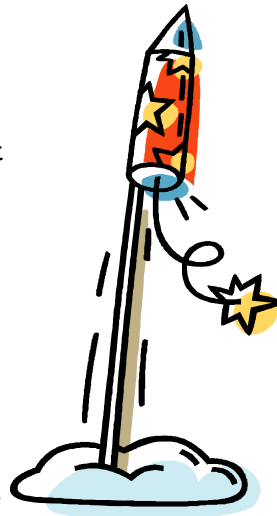
The majority of enrollment in the study is via mail, although patients are welcome to set up a one-time study visit, which takes about 2 hours.

Enrollment has been terrific. We have collected about 400 individuals and are now focusing on collection of family members too. Our study has shown about 50% of families in the U.S. & Canada have more than one family member affected or experiencing symptoms of IC/PBS/CPPS.

Since life can get in the way of people's best intentions, the team has been trying to keep the enrollment process moving forward by scheduling consenting calls, getting forms returned in the pre-paid mail-

ing envelopes, and collecting outstanding sample kits. With the large number of participants, we apologize for any delays. Please contact us if you have not fully enrolled.

You DO NOT need to have a family member participate to be eligible. We are hoping to collect 600 individuals and/or their families. Recommend us to your family and friends and keep the numbers coming.



Children's Hospital,  
Boston

3 Blackfan Circle  
CLS15031  
Boston, MA 02115

Elicia Estrella  
Phone: 617-919-4552  
Fax: 617-730-0253



Email: [Elicia.estrella@childrens.harvard.edu](mailto:Elicia.estrella@childrens.harvard.edu)



## CONTACT US! We would love to hear from you!

1. Give us feedback about the newsletter
2. Future topics you would like in the newsletter
3. Update us on any changes with you
4. Take me off your mailing list
5. Add someone to the newsletter mailing list

### Reply Card

Name: \_\_\_\_\_

Contact Information Changes: (Please Print)

Address: \_\_\_\_\_

Phone: \_\_\_\_\_

Email: \_\_\_\_\_

Clinical Updates:

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Please check here to be taken off our mailing list

Please sign to authenticate:

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