

PROSTATITIS INFORMATION

The Prostatitis Foundation, 1063 30th Street, Smithshire, Illinois 61478 • Fax 309-325-7189 FREE INFORMATION PACKET — TOLL FREE: 888-891-4200

MAPP Research Network Sites Now Recruiting prostatitis patients!!

The Multidisciplinary Approach to the Study of Urologic Chronic Pelvic Pain (MAPP) Research Network has been established by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) of the National Institutes of Health (NIH) to focus on a broader approach to the study of Chronic Prostatitis (CP)/Chronic Pelvic Pain Syndrome (CPPS) in men and Interstitial Cystitis (IC)/Painful Bladder Syndrome (PBS) in men and women, than previously undertaken.

Patients with CP or IC are now being recruited for a new research study called the "MAPP Network Epidemiology and Phenotyping Study"!! By taking part in these studies, participants may help doctors gain a better understanding of how CP and IC affect individuals' overall health and aid them in developing better treatments.

Like many chronic pain disorders, CP and IC are poorly understood and treatments are often not helpful. Our goal in the MAPP Network is to better understand the underlying causes of CP or IC. Through this study we also hope to better understand how CP and IC relate to other chronic pain conditions, including irritable bowel syndrome (IBS), fibromyalgia (FM), and chronic fatigue syndrome (CFS).

The MAPP Network studies are observational, which means we will ask questions and gather information about your health and life for research purposes, but we will not treat you or change any current treatments you may have for your condition. During this study, you will remain under the care of your usual physicians. The MAPP Network plans to enroll a total of 360 patients with some form of CP or IC at nine medical centers across the country, as well as a number of patients with IBS, FM, and CFS.

This is a 12 month study. After the first visit (Screening/Baseline visit), participants will be asked to come back to the clinical center twice during the next 12 months, as well as complete a brief biweekly (every other week) and bimonthly (every other month) computer questionnaires at home in between clinic visits. In addition to the clinic visits and online assessments, during the next 12

months participants will be asked to collect a maximum of 4 home urine samples to aid in our study of how symptoms change over time. Participants will also be given the option to enroll in additional network research studies that will provide new and important information for the main study. To learn more about participating in the MAPP Network study at the below locations, check out the "Recruiting Sites" tab on the MAPP Research Network website at www.mappnetwork.org/.

Research Sites Information For MAPP Network

University of Miami Miller School of Medicine

Miami, FL

Principal Investigator: Thomas M. Hooton, MD

Contact: Gabriel Blaschke (gblaschke@med.miami.edu)

University of Alabama at Birmingham

Birmingham, AL

Principal Investigator: Timothy J. Ness, MD, Ph.D.

Contact: Beverly Corbitt (205) 934-3751

(bcorbitt@uab.edu)

University of Michigan

Ann Arbor, MI

Site Directors: Daniel J. Clauw, MD and Quentin

Clemens, MD, MSCI

Contact: Megan Halvorson (734) 765-8856

(meganeb@med.umich.edu)

Northwestern University, Feinberg School of Medicine

Chicago, IL

Principal Investigators: David J. Klumpp, Ph.D.

and Anthony J. Schaeffer, MD

Contact: Darlene Marko (312) 695-3898

(d-marko@northwestern.edu)

Washington University in St. Louis

St. Louis, MO

Site Directors: Gerald L. Andriole, MD and H.

Henry Lai, MD

Contact: Rebecca Bristol (314) 454-7325

(bristolr@wudosis.wustl.edu) Vivien Gardner (314) 996-8285

(gardnerv@wudosis.wustl.edu)

University of Iowa

Iowa City, IA

Site Director: Karl Kreder, MD, MBA Contact: Mary Eno (319) 384-9265

(mary-eno@uiowa.edu)

University of Washington

Seattle, WA

Site Director: Dedra Buchwald, MD Contact: T. J. Sundsvold (206) 616-4497

(mapprc@uw.edu)

Stanford University

Palo Alto, CA

Principal Investigator: Sean Mackey, MD, Ph.D. Contact: Noorulain Noor (650) 724-0522 *sn*Los

Angeles, CA

<u>David Geffin School of Medicine at University of</u> Southern California

Principal Investigators: Emeran A. Mayer, MD and

Larissa V. Rodriguez, MD

Contact: Suzanne Smith (310) 206-0310

(srsmith@mednet.ucla.edu) Jennifer Soh (310) 206-1757 (jsoh@mednet.ucla.edu)

The research underway above is an attempt to meet the needs of prostatitis patients. With previous research groups two five year research plans have been completed already and one was expanded into a sixth year. It has been very frustrating that a cause and cure for prostatitis has not been found. The MAPP Network is committed to that goal and has adopted this new approach which includes additional specialties other than urology. The NIH is making an effort to seek a cause and cure for prostatitis in response to your requests and letters so we need to support these research centers. We suggest you contact the sites nearest you Please study their web site and follow it for additional information. The MAPP Network web site is now public www. Mappnetwork.org.

Answers to questions submitted by patients to the Prostatitis Foundation for Dr Pontari.

1. My husband has a lot of pain at ejaculation. We have seen the doctors but have had no relief. Have you heard of anything like this before? Is there any cure?

Pain with ejaculation is a common symptom of Chronic Prostatitis/Chronic Pelvic Pain Syndrome (CP/CPPS). This is one of the symptoms we ask about on the symptom score used to evaluate this condition. This is a condition I see many times per week in the office. There are many different ways to treat this but generally we look to find a specific cause such as infection or stones. If no specific cause is identified, we use medication to try to relieve the symptoms.

2. My doctor is considering a transurethral heat ablation for my long term prostatitis. Do you think that is a good idea?

Transurethral heat ablation is a technique used for treating lower urinary tract symptoms. Men with frequency of urination, slow stream and hesitancy may be improved. There is not much data to suggest that it will improve pelvic pain. If the procedure is for voiding symptoms, this sounds reasonable. I would ask the doctor what specific symptoms he or she is looking to improve.

3. Do you think it is harmful to stimulate myself to near an ejaculation and not complete the ejaculation at the last minute?

I know of no studies that indicate that this is harmful. If you are having pain from this I would consider refraining from doing it.

4. My son is 28 yr's old and has had a couple of bouts with prostate inflammation, he has been given medication both times and the medication seemed to have cleared his problem. My question is could his past prostate inflammation problem have any impact on having children?

I know of no data to suggest that a history of prostatitis will make it more difficult to have children later on. In any given couple having difficulty conceiving, 1/3 of the time it is due a problem with the male partner, 1/3 of the time the female partner, and 1/3 of the time a problem in both partners. If there is a history of unprotected intercourse for one year with no successful pregnancy, then it is recommended to have an evaluation. However, I do not think your son is at higher risk than the rest of men without a history of prostate inflammation.

5. What are your current feelings about prostate massage?

I do not think it is harmful. In some men it seems to help the symptoms of prostatitis. If this is to be done, three times per week for 6 weeks seems to be a reasonable length of time. In addition to actually clearing the prostate, it may act to help relax the muscles of the pelvic floor.

The National Kidney and Urologic Diseases Information Clearinghouse is at, 3 Information way, Bethesda Md 220892-3580, Phone 1-800-891-5390. Their Internet location is http://kidney.niddk.nih.gov/. In our information packet to new patients we include two of their publications, Prostatitis: Disorders of the Prostate. We also include Medical tests for Prostate Problems. Look under: A-Z list of Topics and Titles. These two fact sheets are available by calling 800 891 5390. You can read them on the clearinghouse webpage also.

The Prostatitis Foundation thanks Farr Labs LLC. for their support of this newsletter and our webpage. They are the makers of ProstaQ for Chronic Prostatitis. For more information visit ProstaQ.com or call 877-284-3976.

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