

Eagle-Barrett Syndrome,

(also known as Prune Belly Syndrome), is:

- a rare birth disorder
- affecting 1 in 40,000 births,
- predominantly males, resulting in
- lacking abdominal muscles,
- renal defects, with a possibility of
- heart,
- lung,
- bone,
- hearing,
- and other defects as well.

Statistics show around 50% of these children die before their second birthday.

Most of these children have to endure many hospitalizations and surgeries. They usually grow to adulthood never having met another person like themselves and thinking that they are THE ONLY ONE. The Prune Belly Syndrome Network, Inc. was founded in 1996 by Brian Beirne. Brian had PBS and passed away April 16, 2000. The network continues to educate people about this rare disorder. We hold annual conventions to bring together those affected by PBS and doctors with experience dealing with it.



PBS is an international disorder and the PBSN is an international organization. We have members from the United States, Canada, England, France, Australia, Germany, Sweden, Ireland, and Peru to name a few countries.

We may speak different languages but the need and the caring are the same.

Here's what some of our members have to say:

"I found out when I was 16 weeks pregnant that "something" was wrong with the urinary tract of my baby. I was sent by my OB to a "specialist". He told me that there was no hope and that I should abort immediately.

My baby was alive and I wanted it so bad, I just couldn't do it. I decided to carry him to term. We went through the pregnancy with little hope, picked out a casket and burial plot.

I delivered my "no hope child" with a C-section. Yes, he had Prune Belly Syndrome. He has had several surgeries and will need a transplant. He is 13 years old, smart, funny and I can't imagine not having him in my life. If I had listened to the gloom and doom specialist and had an abortion, I never would have experienced the joy that he has brought to my life."

"Finding this web site...made a huge difference in my life."

"This website is the reason we still have our son!"



Prune Belly Syndrome Network



Support & Hope !



Visit us at:

www.prunebelly.org

The Prune Belly Syndrome Network

is a volunteer organization devoted to patient support and to education of the medical community about prune belly syndrome.

The PBSN was founded in 1996 and incorporated on October 9, 1998. Later that same month the first Board of Directors Meeting was held in Pittsburgh, PA. We are currently run by a board of directors consisting of a president, vice president, secretary, treasurer as well as a transplant consultant, pharmacy consultant, youth consultant, and general board members. We hold bi-annual elections and the board is voted on by the members. The Prune Belly Syndrome Network, Inc. is a non-profit organization with 501(c)3 determination under sections 170(b)(1)(A)(vi) and 509(a)(1) of the Internal Revenue Code, issued in May 2001. We coordinate our efforts through our website.

Although, conventional medical wisdom has depicted prune belly syndrome as a devastating, often fatal disease, many can go on to live happy and productive lives with proper medical care. Some children will need several corrective surgeries but others do not, as there are many varying degrees of the disorder.

Many PBS patients have discovered that they can participate in a variety of sports and physical activities with far fewer limitations than was previously predicted. In addition, with medical discoveries and the advancement of fertility techniques, some affected by PBS have gone on to father children. The PBSN has 2 members in their 60's and another in his 70's. A normal life is VERY accessible! We have members who are doctors, lawyers, nurses, musicians, and many other professions.

Welcome!



Here you will find a collection of information about Eagle-Barrett Syndrome which is also commonly known as Prune Belly Syndrome. The Prune Belly Syndrome Network, Inc. provides support for those who have Prune Belly, their families, friends and the health care professionals who treat them. Many professionals have never before treated someone with prune belly.

The picture often appears very bleak . . .

“Your child will never walk”

“Your child will not live a normal life”

But ~ there IS hope!!

We at the PBSN are here to help.

**A person born with Eagle-Barrett Syndrome
CAN live a normal, productive life!**

We offer support from people who understand!

The Prune Belly Syndrome Network has open membership to anyone whose life is in some way affected by PBS, whether by having it themselves, having a child with it, or just knowing someone with PBS. We work with many doctors who are interested in researching and treating people afflicted with prune belly syndrome. We are committed to holding annual conventions for information and support. This is an invaluable source for our members with PBS and to help the parents to learn to better care for their child with PBS.

Our Founder – Brian Beirne, R. N.



"There's so much to say when I first speak to someone about Prune Belly. I am 44 years old and have Prune Belly. I first started the site about a year ago. Until that time I never heard of another person with Prune Belly. I didn't even know it had a name until I was in my 20's. It's difficult to imagine the feelings my mother probably had when I was born."

Brian Beirne
August 3rd, 1997