Welcome!

Our First Newsletter – I am so very excited to share with you our first newsletter from the UPMC Adult Spina Bifida Clinic. I am a physiatrist (pronounced fizz-eye-a-trist) (rehabilitation doctor) and the Director of the Clinic. Our clinic began in 2003, and I became the Director in 2005. Our clinic is funded by the Pennsylvania Department of Health, Bureau of Family Health, which helps us to provide many services for your health and wellness. We are one of the only spina bifida clinics for adults in the region. We offer care coordination services and have partnerships with the Departments of Urology and Neurosurgery, as well as other specialty providers. We also offer a financial assistance program (for those who qualify) to help with items that may not be covered by insurance. Our clinic provides care to adults, including those who transition from care at UPMC Children’s Hospital of Pittsburgh.

We developed this newsletter as a way to keep our patients and families engaged and informed about health and wellness activities in the community, and also to provide helpful tips and updates throughout the year. Our entire team will be writing these newsletters so that you can learn from all of us. We hope you enjoy it. Please feel free to contact us with suggestions for what you would like to see in future newsletters. Written by Brad Dicianno, MD, Director

Meet our Staff

Darcie Ilg, PA-C – I am a physician assistant (PA) and joined the Adult Spina Bifida Clinic in January of this year. I moved back to my hometown of Pittsburgh from Charleston, SC at that time and was extremely fortunate to find such a wonderful group of people to work with, not only the clinic staff but also all of the patients. I love to educate and also to learn. My position here allows me to do both! I have the opportunity to share my own knowledge and also to learn new things from each person I meet. I think what makes our clinic unique is that we get to spend a lot of time with each patient. We get to know everyone really well and they share their experiences with us, including their own ideas and techniques. There is so much to be gained in sharing with others. I am excited to increase my role in the spina bifida community and to continue to make meaningful connections in the future.

Andrea Knapp, RN – I am the clinic nurse for Dr. Dicianno and the spina bifida team. I have been working in the Rehabilitation Department at UPMC since 2005 and became a nurse in 2010. In 2016, I moved from the inpatient rehab spinal cord injury unit to the outpatient office here at UPMC Mercy. It has been a pleasure working with all of you for the past two years, and I look forward to meeting those of you whom I have not yet met. See you next time you are in the office!
Sara Izzo – I am a research associate for our spina bifida clinic as well as a person living with spina bifida who encourages independent living and motivational thinking. I have enjoyed working with our amazing health team and our patients to improve a healthy lifestyle both mentally and physically. My goal is to encourage our patients to face their fears and challenges with a positive outlook towards the future, while helping those around us see life without limits and stereotypes.

Dan McCoy, ACE-CPT – I am a Certified Personal Trainer and working toward a masters degree in Sports Science. My goal is to show people with spina bifida the positive impact exercise can have on overall health and well-being. Having spina bifida myself, I also help patients with ways to improve mental health in exercise as well as every day life.

Sabrina Palmieri, RD, LDN – One of the major goals of the UPMC Adult Spina Bifida Clinic is to improve our patients’ quality of life, and understanding and having proper nutrition is one way you can reach that goal. Good nutrition is an important part of leading a healthy lifestyle. As our clinic’s registered dietitian, I can help you to make positive diet changes and meet your body’s nutritional needs. The available one-on-one nutrition counseling will help to nourish both your body and mind, while supporting long-term goals to improve your overall health and wellbeing.

Talking about Transition
What is transition? – Patients and families may be hearing a lot of information about “transition of care.” Health care transition is getting ready for health care as an adult. The goal of our clinic is to plan for all of a patient’s needs for the changes ahead in your health care. We support the idea that transition is not a one-time event. It is a process that our team will continue to discuss throughout your care. Stay tuned for future newsletters where we will provide tips and resources about your transition needs. Written by Rachel Young, CRNP

What’s Happening at SBAWP
Do you know about SBAWP? – The Spina Bifida Association of Western PA (SBAWP) was founded in 1969 by parents and incorporated as a nonprofit organization in 1977 by Gay Simpson Reigel. The Spina Bifida Association of Western PA (SBAWP) was founded by parents and is a nonprofit committed to improving the quality of life for people with spina bifida and their families. They provide many support services, education and advocate for you. Their programs are designed to help people realize their goals at every stage of life.
Current programs include BluePrints, Family School Partnership, Firefly summer camp and weekend retreats, Gatehouse, Community Services and Wellness Programs. For additional information, please visit the website at [www.sbawp.org](http://www.sbawp.org). Upcoming SBAWP events:

- **Girlfriends for Good Purse Bash**: November 3, 2018
- **Adult Retreat**: November 30 – December 2, 2018
- **Youth/Teen Retreat**: December 7 – 9, 2018

**Neurosurgery and Urology Partnerships**

**Our Urology and Neurosurgery Partners** – Many people with spina bifida have problems with their bladder or kidney. Our partners in the Department of Urology will help with management of incontinence (if you are not able to control when you go to the bathroom), bladder and kidney stones, urinary tract infections (UTIs), and can also perform special testing to understand how the bladder is working and what treatments are available. Our neurosurgery partners will talk with you to make sure you know what care options are available to you to meet your neurosurgical needs related to spina bifida. Please contact the Adult Spina Bifida Clinic if you feel that you need to talk with one of our specialists.

**Research Highlights**

**New Healthcare Guidelines Released** – October 2018 is very important in the care of people with spina bifida because it marked the release of the Fourth Edition of the “Guidelines for the Care of People with Spina Bifida.” The last version was published in 2006 and was outdated because much research has been done in this area over the last decade, including new research on the care of adults.

The process of writing the Guidelines took about 2 years to complete. Dr. Dicianno is the Associate Medical Director of the Spina Bifida Association and Chair of the Professional Advisory Council. He helped to lead the effort as the one of the 3 Co-Chairs of the Steering Committee. Over 100 individuals, including researchers and clinicians from inside and outside the US, as well as adults with spina bifida and family members participated. The guidelines cover 23 health topics, many of which are new, including topics such as physical activity, health promotion and preventive medicine, quality of life, and nutrition and obesity.

Although this version of the guidelines is meant for health care team members who care for people with spina bifida, a patient/family friendly version and a smartphone version are currently being developed. This project was supported by the Centers for Disease Control and Prevention and the Spina Bifida Association. It is hoped that these guidelines will not only guide health care providers but also patients and families, so that people with Spina Bifida can have the best and most scientifically-based care and treatments throughout their ever-longer and higher-quality lives. You can view them at [spinabifidaassociation.org/guidelines](http://spinabifidaassociation.org/guidelines). *Written by Brad Dicianno, MD, Director*
Tools for Techies and Gadget Lovers

Smartphone app for people with hydrocephalus – HydroAssist is a free smartphone app available for both Android and iPhones. It was developed by the Hydrocephalus Association, a nonprofit organization. It allows you to store information about your shunt, including images from your head CTs, and share this information with doctors, which can be helpful in emergencies. More information is available at https://www.hydroassoc.org/hydroassist-mobile-application/. *Written by Brad Dicianno, MD, Director*

Contact Us

UPMC Adult Spina Bifida Clinic
1400 Locust Street
Building D, Suite G-103
Pittsburgh, PA 15219

Phone: **412-232-8901**
UPMC.com/SpinaBifida