Read stories from patients about their experiences with UAB and other bladder disorders.

Submit your own stories here

Author, JoAnne Lake, is the mother of four grown children, one of whom has neurogenic bladder. She was diagnosed as a patient of neuorgenic bladder in 2009 and shares her life experiences and emotions as a patient, mother, educator, and friend coping with these conditions on her blog: TrudyTriumph.

There is also a book that describes her journey in greater detail, "Beyond Embarrassment: reclaiming your life with neurogenic bladder and bowel" available at TrudyTriumph.com

I'm 63 years old but have had prostate and UTI issues since I was in my mid 40's. I have had Microwave procedures and 3 TURPs to finally get my flow back to normal. After the last TURP, I thought all was fine until one night I wet the bed. I could not understand what was going on and took to wearing diapers at night to prevent wetting the sheets. Then I started to get UTI after UTI even when taking all the precautions to prevent them.

My urologist did an ultrasound and even though I had no feeling or urge to go to the bathroom, he discovered I was retaining massive amounts of urine. He drained approximately 6 liters from me that day and determined that I had UAB Syndrome.

I now have to Cath myself 3 times a day and although I am taking a drug to try and activate the bladder, it is not working. I may have to Cath myself for the rest of my life unless someone comes up with a cure.
- MM, March 2016

I am a 25 year old female who has only recently found out via a urodynamics study that I have
an underactive bladder. My anxiety contributes a lot to this problem as I have difficulty relaxing my pelvic muscles.

In Queensland Australia we don't have sufficient knowledge or help. My urologist just sprung up this information to me quite abruptly and only told me there was two options for me - nightly self catheterization or sacro neuromodulation surgery.

I have previously had to be catheterized for severe urinary retention when I was severely anxious but felt that with treatment of my anxiety my bladder issues would dissipate. No alternative therapies were suggested for me by my urologist when I was diagnosed!

I feel I need a second opinion...
- EH, January 2015

I am a 62 year old Canadian man, very active and healthy, retired and happily married for over 35 years. I have had urinary obstruction issues for many years. I used various medications over the years to treat my condition but as time progressed, they became less effective.

I briefly attempted to use Adavart, but it affected my ability to get an erection almost immediately. It should be noted that up until recently I was on testosterone replacement (Androgel) which I imagine played some role in my condition.

My wife and I were planning an exciting expedition to the Galapagos Islands and Ecuador in January 2014, when I went into almost total urinary retention. A brief catheterization opened my urinary tract enough to get some flow. I consulted with my family Doctor and I knew it was time for surgery. I researched my options and chose a Greenlight Laser surgery to remove the obstruction that was impeding my flow of urine. (prostate was only 40 grams)

The surgery finally took place on April 28, 2014. Six week post surgery I was urinating normally and with great vigor. I noticed over the summer months that there was some slowing and hesitancy in my urine flow, with more difficulty at night.

Ironically I had had a check up with my Urologist in early September. I arrived at the clinic with a very full bladder, voided into the flow machine and the ultrasound showed that I had emptied my bladder. The urologist was very pleased, although I did say to him that I was having intermittent symptoms with urinary retention.

Between September and October this condition degraded further. A few weeks ago, (I believe it was a Friday) after a lovely and intimate rendezvous with my wife, I could barely pass any urine. I took myself to emergency, and finally after about 6 hours, I walked out with an indwelling catheter.
This remained in place for 12 days until the time when my urologist could fit me in for a cystoscopy. He was very disappointed not to find any obstructions impeding the flow of urine out of the bladder, thus coming to the diagnosis that I have an Neurogenic Bladder. He said there was nothing he could do and that there are no cures or real treatments for this disease. I was devastated!

He very quickly set me up with a health care agency that showed me how to self-catheterize. I am still able to void with varying degrees of success on my own, and I am not sure what role the catheterization is supposed to play my in treatment and daily life.

I have stopped using the androgel and I take one 4mg dose of Flowmax daily. Finally, the urologist is going to refer me to a specialist for urodynamic testing.
- MG, November 2014

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I am 26 years old man. I am also suffering from UAB problem. I am trying a lot to overcome this problem. If posible than i will share my treatment to all. Right now i don't have need of catheter to empting my bladder. I can do it myself. I am consurting desi Hakimes for this also. Let see if posible to do something.

For other people who are also suffering from this problem that no one know about it much. Lots of institute try to find out who to over come this problem but sorry to say right now. there is not cure solution available to soon.

Hope we will see a good treatment. Best of luck all my friends  God will help us.
- SC, November 2014

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Because of recurring urinary tract infections I was referred for investigation and it was discovered that I was only partially emptying my bladder.

I was told to use an intermittent catheter after passing urine, which resulted in my bladder refusing to work at all.

This was several years ago and it would appear that I am condemned to using a catheter,
several times a day, permanently.

I still have recurring urinary tract infections.
- JS, May 2014

My mother is 78 years old. She had a heart attack in 2008 and broke her hip the same year. She lives with me and spends her days sitting in the chair.

She doesn't want to leave the house because she always feels like she has to urinate. Recently she has been having trouble emptying her bladder and wakes up in the middle of the night sometimes and screaming, I can't urinate.

She has some dimentia, She has a history of anxiety/ocd/depression. We took her off most of the medication after she suffered a heart attack because her cardiologist told us the medication may have contributed to her heart attack.

For as long as I can remember for the past 50 years, my mom has always had issues with urination. She was always in the bathroom. Sometimes I think it's due to anxiety, but I also think it may be due to her being inactive. I don't want her to take medication because I'm afraid it's going to cause additional problems. Medications masks problems and creates new problems.

This is what I have observed with my mother. If there is something we can do to naturally relieve her symptoms, I would love to hear about it.
- LM, July 2012

I am a 30 years old married man. I was absolutely normal just 3 and half years ago when I started having bladder symptoms which I initially ignored due to lack of awareness. Unfortunately I was diagnosed as a patient of Underactive Bladder 2 years ago by my urologist after undergoing several tests such as Urodynamics, MRI, Blood work etc. My MRI and blood reports were normal but Urodynamics confirmed me as a UAB patient. I am currently on treatment of Alfuzocin and Bethanocol, and also trying some homeopathic treatment.

Inspite of all these medications, I am still suffering from bladder underactivity and quality of life is really compromised. When I think of future I really get worried as I am not only a husband but soon going to be father too. However, I strongly believe that my bladder problems can improve and may be cured as I am still young and have no history of accidents or trauma . I am neither
diabetic nor hypertensive and I highly believe this condition can be treated well provided enough medical and research attention.

I also would like the patients of UAB to have communication with each other which may provide social and emotional support to patients knowing that there are other people suffering from the same problem.

If my story can help your website and through your website the rest of world patients, I will feel proud of myself that at least I have done minor contribution to fight against UAB. In fact if there are more young patients, they may also open up and share too after they learn about my condition.

In fact I will keep updating my experiences through your website as sometimes my conditions are worse and sometimes they improve. I am analyzing these days all my activities and diet which may relate to the improvement in disorder and which other patients can try and may help them too.

I must congratulate your team working on this cause, and all my best wishes are with you to come out with flying colors. I will feel proud if I can be a part of your noble vision.

- GP, March 2012