Patrick Fisher
Starting An Us TOO Support Group

I had severe urinary incontinence after my surgery in 2010. While my surgeon was an exception to the rule and provided me with extensive information about the risks versus benefits of other treatment options and provided urinary incontinence treatment, traveling the path to full recuperation was still a long road for me. By 2012, I had had multiple therapies for incontinence, but grew increasingly frustrated with the idea of having to use pads.

So, I started to seek additional support systems and did some research on the internet. That was when I happened upon an Us TOO chapter located in Batavia, NY, not far from Rochester, only to discover it was no longer functioning. Then I discovered there were Us TOO chapters in Buffalo and New York City, but those were a hundred or more miles away. There was no Us TOO chapter in Rochester.

I then contacted the Us TOO headquarters and talked with Terri Likowski. Terri shared that Us TOO also hoped to form a Rochester chapter.

Did Us TOO provide training or guidance on setting up a group?

Patrick: Us TOO is a global nonprofit with more than two hundred chapters in the United States and other countries. They provide access to support and education for those affected by prostate cancer. They have done a great job helping survivors and seeking sponsors (typically pharmaceutical companies) to fund publications about prostate cancer screening, imaging, diagnosis, treatment options and emerging research.

Initially, I just followed my instincts. When I was diagnosed with severe urinary incontinence, I retired from the University of Rochester Medical Center where I was a community educator for HIV vaccine trials sponsored by the National Institutes of Health.

I developed an ad and wrote a short article about the need for a local prostate cancer patient education effort. The ad identified a date and a location for our first meeting and invited like-minded people to attend. Terri Likowski provided me with a contact person at a well-known pharmaceutical company that manufactures one of the medications we use by prostate cancer survivors. We decided early on those chapter meetings had to be more than a bitch session where men could complain. The focus had to be on patient education that increased awareness about treatment options and side effects. We also decided that our meetings had to be facilitated by urologists or subject matter experts.

And, so, Us TOO Rochester was formed at that first meeting in November 2012. We continued to conduct our meetings in a church basement, which we rented for an evening meeting with a coffee bar, wine, and a vegetable and fruit tray. The total cost was under $700. The pharmaceutical company covered all expenses, including the 35 invitations to urologists and oncologists.

My expectations were low. I thought we might get eight to ten people. But much to our surprise, the room was packed. That first meeting made it clear: peer support for survivors and prostate cancer patient education were efforts that our community would indeed support.

More astonishingly, there were a few urologists in the room from different hospitals and urology centers that also wanted to support us and saw the need for such a group. That immediately gave us contacts within these various medical organizations.

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Patrick: We have been meeting on
second Thursday evening of each
month since 2012.
Most of our meetings have been
at the Jewish Community Center for
Greater Rochester. Their Senior
Resource Program allows our
Chapter to meet in their conference
room for free. I schedule a subject
matter expert to facilitate each
meeting. The topic changes from
month to month. Everyone leaves
feeling more informed about that
month’s topic than they did when
they walked in.
How do you select the topic?
Patrick: At first, I suggested topics
and found local providers willing
to conduct presentations. In recent
months I formed a Working Group
of survivors who help select topics.
The Working Group now also helps
organize local events.
What is your group’s current
relationship with Us TOO?
Patrick: The Us TOO home office
provides support to chapter leaders
with monthly leader calls and a leader
resource page on their website. They also provide forms and personnel
to help ensure that chapter leaders
have the guidance they need and
that local printed materials correctly
represent the Us TOO logo and brand.
When we conduct a fundraising event,
checks are made payable and sent to
Us TOO so donors can benefit from
the 501(C)(3) charitable deduction.
A percentage of funds raised from our
events support the Us TOO home office
to help defray the cost of printed
materials and resources provided to
 chapters. This agreement also makes it possible for our chapter to raise
funds without the hassle of maintaining
a private checking account...
For example, every year, Us TOO
hosts the SEA Blue Prostate Cancer
Walk & Run in Chicago. I followed
their model and created a SEA Blue
Ribbon Walk for Prostate Cancer in
Rochester. We’re hosting our third
walk this summer. At the first one,
we had approximately 80 participants,
a handful of sponsors, and raised about
$10,000. Last year we had more than
400 participants, many more sponsors,
and raised about $25,000. From the
proceeds, we made a donation to the prostate cancer patient survivorship
fund at the University of Rochester
Wilmot Cancer Institute, a local cancer
treatment facility and prostate cancer
research center.
Now we’re looking for benevolent
sponsors for next year and hope
to grow even more.
Do you have any advice for men starting
a local support group?
Patrick: Don’t be afraid. Don’t be
timid. Talk it up with peers. I bet
if you pick six of your male friends,
you’d find that at least one of them
is also dealing with prostate cancer
and may be willing to help.
When I started this chapter, I went
to the breast cancer coalition here
in Rochester, got an appointment with
the Executive Director and asked how
they got started. She was very eager
to share ideas. I executed some of
her suggestions. I also invited her
to speak at our first meeting about
the benefit of patient support groups
for people with cancer.
My suggestion for those interested
in starting a local chapter is to first
contact the folks at Us TOO. Then,
identify a venue, which could simply be
a church basement or a local restaurant.
It doesn’t have to be anything fancy.
Try contacting a local urologist to see
if he or she will facilitate a discussion
group at the first meeting. Consider
placing a short, well-phrased line ad
into your local Penny Saver.
Us TOO Rochester has accumulated
over 45 urologists, oncologists and
pelvic floor therapists who have
facilitated our meetings, all at no
cost. At each meeting, I provide a
sign-up sheet requesting phone
numbers and email addresses for the
purpose of future communications
related to prostate cancer. I create
a simple flyer for each month’s
meeting and then distribute it to
all of the providers and people who
have attended meetings.
Over time, our chapter has obtained
the trust of these medical providers
who now promote our meetings
within their urology and oncology
offices and often refer their patients
to our chapter for additional support
and information about treatment options.
But, reaching out to Us TOO is the
way to get started. Have a conversation
with Terri Likowski. Us TOO makes it
easy. It doesn’t make any sense
to reinvent the wheel. You might
be starting a new group in your area,
but this has been done time and time
again in locations across the country
and around the world. All you have
to do is follow their model.
Have you started any other programs
with Us TOO?
Patrick: Yes. Us TOO has a program
called Community Conversations.
They select four cities with Us TOO
chapters to conduct a lengthy community conversation about topics concerning
prostate cancer. Us TOO Rochester
was selected as a location for a
Community Conversation on Saturday,
June 17, 2017. The University of
Rochester Medical Center Urology
Group and Wilmot Cancer Institute
will host the event. Our venue is
a local country club in Rochester.
We’re looking forward to this event:
June is National Men’s Health Month.
Is there anything else you’d like to add?
Patrick: While I was diagnosed with
severe urinary incontinence following
my surgery, by being faithful to pelvic
floor therapies and adhering to self-help
recommendations, today I am
no longer wearing any pads and have
retrained bladder control. The process
of retraining my bladder (and my brain)
required 18 months and a lot of patience.
One day I stayed dry all day and have
been pad-free ever since. I am proof
that it is possible, and that over time
even challenging recuperations can
lead to success.
I have no regrets about choosing surgery.
I have learned there are many men
who agree and that many others have
no regret about choosing radiation,
proton beam radiation, or other
treatments like hormone therapies.