

# GIST not the toughest foe for John and Kathy Weir

Former detective and his wife have faced, met 12 years of challenges

By Kathy Weir

**G**lobal warming had finally reached the northern peninsula of Michigan, making Sept. 22, 1990, a beautiful summer-like day. John had worked overtime the night before as security at the annual Tough Man Contest. The Soo (Sault Ste. Marie, Mich.) is full of tough people and John had to break up a fight that had spilled outside the hockey arena. The next morning, Saturday, John had to interview a child who had been sexually abused. John's gentle, kind nature and love of children made him invaluable to the unit trying to prosecute child abusers.



**John Weir**

He no sooner came home than the phone rang again. John didn't say much but I remember his last words to me as he put on his SWAT team uniform, "Don't worry, I can handle it." I didn't worry. John had a wall full of trophies for combat-style speed shooting, and his lumberjack activities in his off hours made him the strongest man I ever met. John had demonstrated his stamina when he tracked four escaped prison inmates in snow up to his waist until he wore them

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Battling GIST with Gleevec (STI571)



## LIFE RAFT GROUP

April 2003

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# Relapse survey: Is bigger dose better?

## Fewer year-plus patients on larger Gleevec doses experience relapse

**A** majority of GIST patients on Gleevec for more than a year continue to do well. For those whose cancer becomes resistant to Gleevec, a few new drugs are in development.

Those were two of the key points made March 31 when a quartet of Life Raft Group members traveled to the Novartis Oncology office in Florham Park, New Jersey, U.S.A.

The meeting began with a ceremony inducting the 10 participating Novartis officials as "honorary" members of the Life Raft Group. Each Novartis participant was given one of the new Life Raft Group pins.

Norman Scherzer, the Life Raft's executive director, then led a review of the Life Raft's informal relapse poll that surveyed members with metastatic GIST have been treated with Gleevec for more than a year, and who experienced tumor shrinkage.

Those Life Rafter reporting relapses after initial tumor shrinkage numbered 18, while 65 reported continued stability while on Gleevec, said Scherzer. Also, the informal survey indicated that the higher the dosage, the less likely the chance of relapse.

- Of those who started and stayed on 800 mg. Gleevec, only one person



**Life Raft Group members at the Novartis Oncology office in New Jersey, U.S.A, from left, Jerry Call, Marina Symcox, Norman Scherzer, David Josephy.**

reported disease progression.

- Of those who started at 800 mg. and had their dose reduced to 600

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## John's story: In the darkness was a man with a knife

From Page 1

down into surrender. He was also patient, resourceful and street smart. Nothing could hurt John.

Our 19-year-old son drove John to work so I didn't have a chance to kiss him goodbye. He went to work at about noon. Night came, and I waited up. I never pried into John's work. I trusted him and never knew when something like this would end. I tried to sleep.

Around 4 a.m., I uncharacteristically called the office. Sgt. Bill Payment told me that John was about to wrap things up and they would call me when he was headed to the hospital. That confused me, but I didn't pry.

Later I learned that John was in a barricade situation with a man named Michael, a 6-foot-5, 38-year-old paranoid-schizophrenic who was threatening to kill his parents and burn the house down around them. His parents refused to leave the house.

I later learned that John was alone at this standoff because Mike hated police officers though he knew and trusted John. John had dealt with Mike before, and told me how he'd talk Mike out of hurting himself or someone else and would gently take him to the nearest mental hospital — only to be told by the psychiatrist or social worker, "You cops wouldn't know crazy if you saw it. It takes a lot of education to judge if a person is violent and you don't qualify." They would then release Mike, and John would wryly joke, "Mike gets home before I do." Then he'd sadly say, "He is going to hurt someone someday and there is nothing I can get the doctors to do about it."

So it was John, not the mental health professionals, who again had the job of handling Mike that night. The state police, who had special training and protective equipment (like visored helmets) never showed up. John didn't get backup or relief in an almost 20-hour standoff. The other city officers working that night were all rookies and were not even allowed to drive by the barricaded house because it might upset Mike.

At 4 a.m., when I'd felt enough dread to call the office, was the very moment Mike calmly told John that he

sprung out at John with a 10-inch boning knife. Mike had been threatening to "lobotomize" John all day. He must have aimed well because the knife plunged into John's right eye and tore behind the left eye, moving deep into his brain. Still conscious but now totally blind, John made his way upstairs. He asked for help and was still conscious on arrival at the hospital.

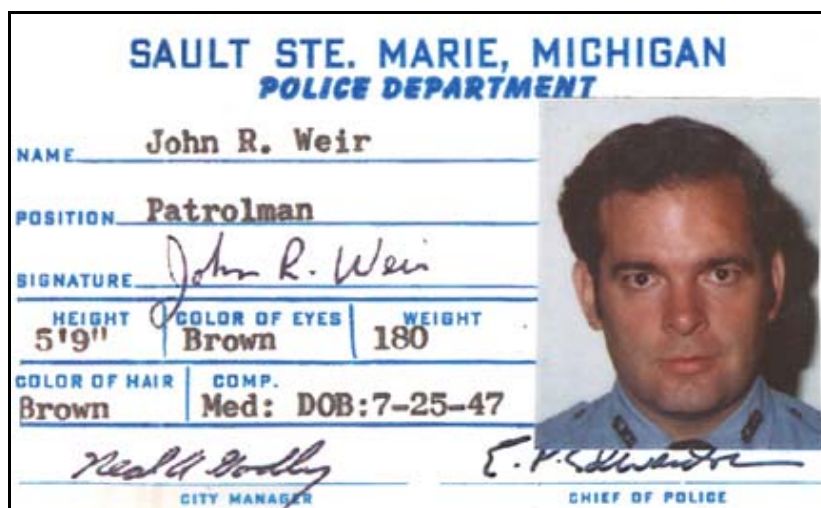
I didn't get the call until around 6 a.m. I had gone to sleep and in my half-awake state I remember Bill saying to me, "Kathy, they need you at the hospital." I knew Bill had mentioned hos-

pital at 4 a.m., so I felt sleepy confusion. I asked why on earth they needed me there. Bill said, "They need you at the hospital because something happened. I'll pick you up."

It hit like a stun gun to the chest. I couldn't figure out how to change into my clothes. I tried to wake up our son to watch his 12-year-old sister. I hung

onto the upstairs railing and weakly called for him until it finally came out audibly enough to awaken him, "It's your dad!" That was all it took. Young John tumbled down the stairs, ran to his car and hysterically drove off. This woke our daughter, who was somehow able to sense what had happened and began to scream, "Daddy! Daddy!"

We made it to the hospital in time to see John with his right eye hanging out of his head, covered in urine and blood, his clothing cut off and being manually resuscitated while he seized violently. He had long ago lost consciousness. We would never again speak to the person we'd known and loved.



was ready to go to the hospital. John began to remove the barricade when Mike dumped a bucket of urine he had collected right over John's head. Mike threatened to set the house on fire. John called *his supervisor* at home and asked for relief.

When the young officers got there, John said the orders were to get Mike out. Without any protective gear, armed with only a can of mace, John gave the order and charged down the basement stairs to where Mike was going to set his fire. I think John felt that with surprise and strength, he could disarm Mike before anyone else was hurt. He had that kind of ability and confidence.

Mike was hiding in the darkness and

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## Life Rafterers in New Jersey



After meeting March 31 with Novartis officials in New Jersey, U.S.A., Life Raft members gathered at the home of Norman and Anita Scherzer in Little Falls, New Jersey. Enjoying the occasion were, from left, Marina Symcox, Jerry Call, Anita, Bernie Kaplan, David Josephy, Norman, and Tricia McAleer. Marina and David are members of the science team headed by Jerry; Bernie is on the Life Raft's board of directors, Trish is the Life Raft's administrative assistant and, like Anita, must put up with Norman, the executive director.

## Weir: The attack forever changed his life — and Kathy's

From Page 2

Today John is blind, suffers from paralysis and spasticity, and has no ability to access his past life without me prompting his memories. It took several years of fighting, and many stays in inhumane institutions to get the rehabilitation and services he needs. After he woke from the coma, he would ask to go home. I would get him to my car and get him home — only to have him scream that he wanted to go home. I would try to comfort him and

he would push me away because he couldn't remember he was married. He was incontinent but still strong enough to thrash out and wreak destruction on the bed, making messes with bodily fluids and feces. He could still pull an arm out of a socket and cause a concussion, and no physical therapist could undo the pretzel he'd turn into due to his spasticity. He had constant flashbacks of that night and others, and his mind was always at work fighting

demons that had finally come to destroy the angel who couldn't stop giving and doing and helping. Most terrible of all, I could not give him home no matter how much I tried.

It would take a book to tell of all that our family has suffered over the past 12-plus years. After bankruptcy, the loss of our home and my business, and the fast falling away of almost every friend we ever had, we traveled to

**See John today, Page 6**

## Survey

From Page 1

mg., four relapsed.

- Of those who started at 800 mg. and had their dosage reduced to 600 mg. and then to 400 mg., five patients relapsed.

- Of those who started and stayed on 600 mg., no relapses were reported.

- Of those who started and stayed on 400 mg., eight relapsed.

“The consensus of the meeting participants was that the relapse group was too small — thank God — to draw firm conclusions,” Scherzer commented after the meeting. Instead, he said, “the data should be considered preliminary and used to raise sensitivity levels to possible correlations, rather than to draw any conclusions at this time.”

Nonetheless, it may be prudent if a patient is on 600 mg. or above, and not having significant difficulty with side effects, to remain at that dosage until more is learned about long-term drug effectiveness.

There was a discussion about whether GIST should be treated with a traditional cancer treatment paradigm — which utilizes the maximum tolerated dosage — or continue to follow the clinical medicine paradigm — which utilizes the minimum dose needed to produce a result. There was no consensus other than any approach needs to consider individual needs.

An interesting focus of the Life Raft Group analysis was that 46 percent of all patients responding reported one or more dosage changes. That raised the issue of whether such changes are factored in by clinical researchers when they compile their reports and analyses. The answer: Generally not. Researchers usually follow the U.S. Food and Drug Administration rule that calls for reporting by the “initial intent to deliver dose” — the starting dosage. There was a developing consensus at the meeting that this approach should

## Relapse data, GIST patients with metastatic disease

On Gleevec for more than one year with good initial response but subsequent relapse

Dosage (first number is the starting dosage; second is the dosage that preceded the relapse)	Male	Female	Totals
800-800	1	0	1
800-600	3	1	4
600-600	0	0	0
<b>Subtotal — 600 or more at relapse</b>	<b>4</b>	<b>1</b>	<b>5</b>
800/600-400	2	3	5
400-400	6 *	2	8
<b>Subtotal — 400 or less at relapse</b>	<b>8</b>	<b>5</b>	<b>13</b>
<b>TOTALS</b>	<b>12</b>	<b>6</b>	<b>18</b>

\* Two patients had been reduced to 300 mg prior to relapse.

be reconsidered.

### Other Drugs:

The Novartis RAD trial is for GIST patients not responding to Gleevec. The trial calls for 600 mg. of Gleevec plus the new RAD drug given daily. RAD is similar to another drug called Rapamycin (or Rapamune), made by Wyeth.

The trial started last fall in Belgium with seven patients. One was removed from the trial for a lack of response while six patients remain on the trial and it can be surmised that they are at least stable. A second trial for six patients will soon begin at Dana-Farber Cancer Institute in Boston.

This is another new Novartis drug, PKC412, that is expected to go into clinical trials within the next year if nothing untoward develops during pre-trial research. This drug will be given along with 600 mg. of Gleevec.

Next in the Novartis pipeline is PTK787, another drug which targets C-Kit.

These drugs are in addition to the new Sugen drug for GIST patients resistant to Gleevec, now in phase I trials at Dana-Farber and at Memorial Sloan-Kettering in New York City.

## Those at the meeting:

**For the Life Raft Group:** Norman Scherzer, executive director; Jerry Call, Science Team leader, and David Josephy and Marina Symcox, Science Team members.

**For Novartis:** Dr. Deborah Dunsire, senior vice president and North American regional head of Novartis Oncology; Barbara Kennedy, executive director of Oncology Scientific Operations; Dr. Sandra Silberman, Gleevec clinical project leader; Dr. Laurie Letvak, global head of the phase IV Gleevec program; Dr. David Lebowohl, executive director of Oncology Development (RAD trial coordinator); Carl Keubler, director of the Gleevec brand team; Anthony Venditti, vice president of marketing and business analysis; Howard Godman, global brand manager of Gleevec; Monique Ben-Am, patient access program manager (Novartis international patient assistance program); and Dr. James Jaffee, Gleevec global project leader.

# Cancer legislation needs support now

**S**upport for the Access to Cancer Therapies Act is receiving overwhelming support from advocacy groups, including a coalition that encompasses the United States' biggest cancer organizations.

The Cancer Leadership Council has expressed enthusiastic support for legislation introduced by House Republican Conference Chairperson Deborah Pryce (R-Ohio) to provide the latest cancer therapies to senior citizens.

Medicare currently covers only cancer drugs given by injection and a limited number of oral drugs that have an injectable equivalent. Many new cancer therapies are available only in oral form and therefore are not covered by Medicare. This flaw in Medicare deprives cancer patients of many promising new therapies, including targeted therapies that often have fewer side effects than traditional chemotherapy.

The immediate beneficiaries of expanded Medicare coverage will be survivors of breast and prostate cancer, chronic myelogenous leukemia, gastrointestinal stromal tumor, and multiple myeloma, but many more cancer patients will benefit in the future.

It is estimated that, over the next decade, as many as 25 percent of new cancer therapies will be available only in oral form, and enactment of the Access to Cancer Therapies Act will guarantee that the advantages of these drugs are enjoyed by senior citizens.

The Access to Cancer Therapies Act was supported by 328 representatives and 57 senators in last year's 107th Congress. The CLC urges prompt House and Senate action on this legislation in the 108th Congress.

Here's what you should do to support the Access to Cancer Therapies Act:

- Contact your federal legislators, both your member of the House of Representatives and your U.S. senators. Send them an e-mail, a letter or fax, and give them a phone call.

## Some tips on communicating effectively with your legislator

### Personal Visits

By far this is the most powerful. Stop by their state regional office and let them know that you want them to pass this bill now.

Do not underestimate the power and influence of a staff member; therefore, conduct a meeting with staff just as you would with the legislator. Be brief; your visit should require no more than 15 minutes for you to make your point. Encourage questions and elicit discussion of the legislator's position. Prepare a one-page fact sheet to use during the meeting as a reference and leave this for the legislator and staff. Send a thank you note expressing appreciation for their time and reiterating your position on the issue.

### Letter Writing

Get to the point right away. Your letter should be one page or less. Tell them who you are, why you are writing, and what you are asking your legislator to do. Include the bill number and title.

Don't use form letters or send copies. Each elected official should receive an individual, personalized letter. Do not use your vote as a threat

or bribe. Do not overstate your case or personal experience; the most effective letter is clear and concise.

### Phone calls

Call either their Washington, D.C., office or their district office. Often telephone calls made to the legislator's district office are the most effective. Ask to speak with the health care legislation staff member. When speaking with the staff member, state your name, that you are a constituent, and the reason for your call. Limit your call to three to four minutes and use written notes to keep you on topic. You want them to be VERY clear about your message. Leave your name and contact information with the person you are speaking. This is important — they respond best to their own constituents.

### E-mail

As with letters, you are most effective if you keep the e-mail short and to the point. Legislative offices are flooded with e-mails. State who you are, your address (so they understand that you are their constituent), and your concern.

- E-mail to everyone you know and ask them to do the same. No, that's not overkill. This legislation was supported by an overwhelming majority of representatives and senators last year but stalled in committee. Legislators got too busy doing other things and Access to Cancer Therapies was pushed off to the side. That won't happen again if enough people press their lawmakers for action.

To e-mail your House representative,

get on the Internet and see <http://www.house.gov/writerep/welcome.html>. If you don't know your legislator's name, that's OK; you can type in your zip code and you'll be directed to your representative.

To contact your senators, see [http://www.senate.gov/general/contact\\_information/senators\\_cfm.cfm](http://www.senate.gov/general/contact_information/senators_cfm.cfm). This Web site gives both the snail mail address of your senators and e-mail links.

## John today

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wherever we could find help, ending up in Battle Creek. During those years our kids married and left. Like all the king's men, I would never be able to put the family back together again.

It wasn't until I was able to bring John home all the time, starting around 1996, that he really started to progress. I felt like I was shackled to his bedside but found a lawyer who helped us get the city to provide the help we needed to give us some quality of life.

Now we sleep together in the same bed every night and we eat out once a week. John basks in the care and love that I and the nurses' aides give him. He has a killer sense of humor and though he can only manage one-liners, they can be zingers. He is still the compassionate great listener he always was and he squeezes my hand with his only functional hand at every opportunity. He loves music and the radio. He still loves children and whenever anyone has a new baby they still think of John.

Last year in May I even dared to bring John back to the Soo for the first time in 11 years. The city named May 7 in his honor and John was able to converse simply with family, friends and co-workers who had not seen him in years.

The rookie cops are all grown up now, as are all the children John used to spoil. People cried to have him back that one day and I knew John was glad to be alive and that people still cared about us, after all.

When the cancer was diagnosed this year, I could not believe it. Then I thought that maybe God meant to take John to heaven where he could be whole again, even though he had lived through years of the worst. Maybe God knew I was worn out and couldn't take any more. But I knew that John didn't want to die and I wasn't ready yet to be free. I begged God for more time but not more suffering. I knew I



**Kathy and John Weir are pictured last August, a few months before John's cancer began to manifest itself with life-threatening symptoms.**

couldn't put John through any more.

The answer came in the form of a miracle drug that we hope will give John the extra time we feel we need to just be together a little longer. For some reason we desperately want the Gleevec to work and can't wait for John's first follow-up right after Easter. I hope John is given new life

this Easter because his worth and value as a person have not been diminished one iota, even though he can no longer walk through snow up to his chest with a tree on each shoulder, or rescue children from abusers.

We feel blessed by this group. You

**See John, Page 7**

## In Memoriam

There have been 25 deaths in the Life Raft Group to date:

**Debbie Nance**, 38, Oct. 2, 2000, wife to Eddie, mother of Chris.

**Jim Ackerman**, 49, Jan. 16, 2001, husband to Betsy, father of Jill and Tom.

**Jim Perham**, 63, May 2001, husband to Karen, father of Craig, Kathy, Jennifer.

**Amy Barney**, 25, June 10, 2001, wife to Reed, mother of Joshua.

**Jeff Prichard**, 52, July 11, 2001, husband to Joyce, father of Gregory and Scott.

**Ron Martinez**, 60, July 25, 2001, husband to Jo Ann, father of Ron, Wendy, Natalie.

**Ehud Nehemya**, Aug. 7, 2001, father to Einat Zelinger, father-in-law of Ophir Zelinger, Hadar Nir.

**Bruce Gunn**, 43, Nov. 8, 2001, husband to

Roisin, father of Seamus, Liam, Brendan and Aislinn.

**Robert Carr**, Dec. 30, 2001, father of Robert, Steven, Scott and Melissa.

**Jonathan Montague**, 23, Jan. 19, 2002, son of Ray and Sheila Montague, brother to Jamie, Adam, Meghan.

**Robert Lecca**, 49, Jan. 28, 2002, husband to Diane.

**Jacob Winfield Waller III**, 67, March 31, 2002, husband to Jerry, father to Rita, Richard

**Mary Golnik**, 50, April 18, 2002, wife to Gary, mother to Timothy

**Ana Maria Baldor-Bunn**, 30, April 19, 2002, wife to Stan, mother to William.

**Stewart "George" Wolf**, 51, April 19, 2002, husband to Maggy, father to Thomas.

**Michael Cornwell**, April 19, 2002, husband to Cathy.

**Jerry Pat Rylant**, 61, May 5, 2002, husband to Pamela, father of four, grandfather to 10.

**Jill B. Meyer**, 53, June 9, 2002, mother of Aliza.

**Todd Hendrickson**, 44, June 29, 2002, husband to Janet, father to Max, Tyler and T.J.

**Chet Duszak**, 79, Oct. 5, 2002, husband to Kay, father to Lori.

**Nora Shaulis**, 42, Nov. 4, 2002, wife to David, mother to Griffin.

**Howard Delapenha**, 41, Dec. 14, 2002, husband to Sandra, father to Joshua and Hannah.

**Kathy Colwell**, 45, Jan. 5, 2003, wife to Tom, mother of Katherine, Mary and Tom.

**Cynthia G. Whitson**, 64, Jan. 19, 2003, wife to Jerry, mother to Steve, Jill, Randy and Donna.

**Abdul Hai**, 76, Feb. 26, 2003.

## John: Thanks to Gleevec, he's winning his battle

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are fighting for every moment of life at the highest level of quality you can attain. You also know what it's like to strain the limits of the medical system, to force it to go forward, even if you have been told there is no cure.

The doctors once said John would never wake up and if he did, that he would never talk or eat and would just be a lobotomized zombie sitting unaware in an institution. But John can now walk more than 100 feet with a walker, if only once a day, if only on good days. He loves the challenge, as always.

*Editor's note: John's first CT scans since starting Gleevec show the drug has stopped tumors' growth and spread; in addition, Kathy reports that John's overall health has improved dramatically. "We have discontinued medicines for cholesterol, blood pressure and sugar. His polycythemia seems to have magically resolved as well. He is in a good mood and no pain."*



**As Kathy looks on, John Weir is greeted by the chief of police and lieutenant at the Sault Ste. Marie police department last May 7, the day named in John's honor.**

# THE LIFE RAFT GROUP

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## Who are we and what do we do?

The Life Raft Group is an international, Internet-based, non-profit organization providing support through education and research to patients with a rare cancer called GIST (gastrointestinal stromal tumor). The Association of Cancer Online Resources provides the group with several listservs that permit members to communicate via secure e-mail. Most members are being successfully treated with an oral cancer drug Gleevec (Glivec outside the U.S.A.). This molecularly targeted therapy inhibits the growth of cancer cells in a majority of patients. It represents a new category of drugs known as signal transduction inhibitors and has been described by the scientific community as the medical model for the treatment of cancer.

## How to join

GIST patients and their caregivers may apply for membership free of charge at the Life Raft Group's Web site, [www.liferaftgroup.org](http://www.liferaftgroup.org) or by contacting our office directly.

## Privacy

Privacy is of paramount concern, and we try to err on the side of privacy. We do not send information that might be considered private to anyone outside the group, including medical professionals. However, this newsletter serves as an outreach and is widely distributed. Hence, all newsletter items are edited to maintain the anonymity of members unless they have granted publication of more information.

## How to help

Donations to The Life Raft Group, which is incorporated in New Jersey,

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**Donations, payable to The Life Raft Group, should be mailed to:**

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## Disclaimer

We are patients and caregivers, not doctors. Any information shared should be used with caution, and is not a substitute for discussion with your doctor.

As for this newsletter: read at your own risk! Every effort to achieve accuracy is made, but we are human and errors occur. Please advise the newsletter editor of any errors.