

Chicago area patients seek a 'center of excellence'

University of Chicago is treating 30+ GIST'ers, evaluating new therapies

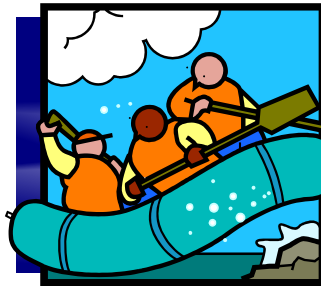
The Chicago chapter of the Life Raft Group has been looking for a "center of excellence" for GIST in the area, and the University of Chicago appears to be answering that call.

"One of our concerns is that we have been unable to find a center of excellence for GIST patients in the Chicago area," says Richard Kinzig, coordinator for the Chicago chapter. "Most of the knowledge is based in OHSU in Portland, Memorial Sloan Kettering, M.D. Anderson or Dana-Farber. Trials occur at these locations for Gleevec, Sugem and drugs such as Novartis' RAD-001, PKC-412, PKC-787, etc. There must be hundreds of patients in the Chicago area that are in need of the latest technology and treatment options who would avail themselves of a center for GIST treatment."

Dr. Hedy Lee Kindler of the University of Chicago has responded to those

See CHICAGO, Page 2

Battling gastrointestinal stromal tumor



LIFE RAFT GROUP

October 2003 In memory of Frank Weigand Vol. 4, No. 10

Record total raised for GIST research



Photo by Ben Chudnov

Tania Stutman poses with a flock of youngsters (her grandchildren and their friends) at the third annual Walk for a Cure, which raised a record amount for GIST research. See "Rain can't dampen ...", Page 3

Progress on fund-raising and many other fronts

By Norman J. Scherzer
Life Raft Executive Director

More than 30 Life Raft Group members have joined together to form the first Thanksgiving Fund-raising Committee. Representing families from throughout the United States and from several countries, the committee will launch this vital fund-

raising campaign as this newsletter begins to make its rounds. Co-chairpersons Gerald Knapp and John Poss are heading this vital effort to sustain and expand the Life Raft Group's many life-saving programs, including our efforts to assemble and disseminate information about drug resistance and strategies to respond to it.

Both Gerald and John are optimistic that Life Raft members, families and

friends will respond warmly to this appeal.

NCI MEETING

The Life Raft Group was well represented at the National Cancer Institute's Sarcoma Progress Review Group, an international panel of experts assembled to draft research recommendations to the NCI for sarcoma

See PROGRESS, Page 2



LIFE RAFT LUNCH — Enjoying a brown bag lunch Thursday, Oct. 16 are, from left, Administrative Assistant Trish McAleer, Executive Director Norman Scherzer, LRG Medical Research Assistant Pamela Barckett, LRG member Steve Rigg, IT Director Jim Roy, and LRG Secretary-Treasurer Bernie Kaplan. Steve Rigg happened to be in the area on business and stopped by to see the new Life Raft Group office. Bernie Kaplan was also there to see the office and for a teleconference for area group coordinators.

CHICAGO

From Page 1

concerns. Kindler is director of gastrointestinal oncology at the University of Chicago and is in charge of GIST research. Kindler writes: "... this is an unusual disease which requires expert management, hence we are trying to make UC a Center of Excellence for the management of GIST. I also think it is a tumor with a fascinating biology which makes it ripe for drug discovery. We are currently taking care of more than 30 GIST patients, most of whom are on clinical trials."

The university currently has three Gleevec trials:

The first is for patients with metastatic disease. The trial is closed (not accepting new patients) but current patients are still being followed.

The second is using Gleevec as adjuvant therapy for patients at high risk of recurrence. It recently closed, but with patients on study.

The third is for patients with an intermediate risk of recurrence, using adjuvant (randomization to Gleevec or placebo). This trial is still open.

"We are now approaching the point where quite a few of our patients are now beginning to fail therapy with Gleevec," says Kindler. "For these patients we have several options."

A widely known therapy is the Sugem drug SU11248. U Chicago will soon open the phase III study of SU11248 for patients who have progressed on Gleevec. "Obviously we are very excited that another drug has already made it to phase III evaluation for this disease, and we are delighted to be able to offer it to our patients," says Kindler.

Another one currently being offered is SDX-102. This is a "targeted anti-metabolite" therapy. It is only offered to patients who have a particular mutation in their tumor-loss of the MTAP gene on chromosome 9p. The tumor is screened for this deletion and if it is

PROGRESS

From Page 1

cancer research.

Life Raft Group Executive Director Norman Scherzer was one of the 20 persons who helped plan the agenda and select the larger body of 125 participants that met from Oct. 8 through Oct. 11 in Philadelphia. Among this larger group were Life Raft Group members Jerry Call and Angela Reipel.

Norman also served as co-chair of the tissue bank committee whose members included Jerry Call as well as Gilles Frydman, president of the Association of Cancer Online Resources. Work on developing a centralized tissue bank continues and should be expedited by the discussions and recommendations that come out of this forum.

Although participants will keep the recommendations confidential until they are finalized by the 20-member planning group, we can share the overall feeling that sarcoma research

urgently needs better coordination.

The active participation of the Life Raft Group and several other patient advocates in helping to draft a blueprint of cancer research was a key objective of the NCI, and will serve patients well both in the research recommendations and in the new relationships that were developed.

That said, we shall remain vigilant in monitoring the actual outcomes of these recommendations. Readers can learn more about the Progress Review process by going to prg.cancer.gov.

GIST SPECIALIST DIRECTORY

The first international GIST medical specialist directory is up and running on the Life Raft Group Web site, www.liferaftgroup.org. The initial entries include GIST specialist physicians from 12 countries and can be sorted both alphabetically and by location (country and state). This list will

See DIRECTORY, Page 4

See U of CHICAGO, Page 7

Rain can't dampen record 'Walk for a Cure'

A foggy drizzle greeted Robert Stutman as he drove into Rockland Lake State Park, Lot 1, North Side.

Great, he thought. The one day of the year when it needs to be sunny.

The two previous years the weather had cooperated, but not this year. The hundreds of walkers who'd be showing up in the next couple of hours were going to have a cold, wet time of it.

The first to arrive, Robert says, was Thomas, a bus driver for Clarks Town. Thomas doesn't have GIST — "he didn't know anything about GIST," says Robert. Thomas had read about the walk in the Rockland Journal News the day before, and decided to show up. Said the GIST group sounded like a good bunch of people.

Then he gave Robert a \$100 donation.

And so the day began.

Before it was over, more than 250 people would make the three-mile trek around the lake. Amid the rain and cold there would be smiles and laughter, happy exclamations of surprise and greeting as online friends saw each other face to face for the first time. There would be hugs and not a few tears among those with GIST, their families, friends and perfect strangers.

As GIST patient Mel Heller would later note: "It was a long day but a long-remembered day as well — a day, I felt, of altruistic love and of an inspired determination to endure, to raise funds and to overcome ..."

Tania and Robert Stutman started the Walk for a Cure in 2001 to raise money for the GIST Cancer Research Fund, which they also started. To date the fund has awarded a total of \$50,000 to researchers at Memorial Sloan-Kettering Cancer Center in New York, Dana Farber Cancer Institute in Boston, Fox Chase Cancer Center in



Photo by Ben Chudnov

Robert Stutman hands out Walk for a Cure T-shirts as participants line up.

Philadelphia and Oregon Health & Sciences University in Portland.

The third walk, held Sunday, Oct. 19, in Congers, New York, was shaping up to be the best one yet. There were more corporate sponsors, and the walk had gotten a big push from the online group GIST Support International. "We couldn't have raised as much money without the help of GIST Support International," says Robert.

If only the weather would cooperate.

As the start time approached, the drizzle became a gentle rain, which turned into serious rain. Robert picked up a bullhorn, thanked everyone for coming, and thanked the walk sponsors — his wife Tania at his side, prompting, making sure no one was missed.

And then it was time to walk. By that time, Tania says, "it was pouring ... and it was chilly. But everybody had a smile on their face, like the rain and cold didn't matter. It was like in that movie, 'Singing in the Rain.' It was

great."

The rain, Mel Heller would later say, served only to baptize the union of GIST patients, caregivers, and friends old and new.

The walk would succeed in spite of the lousy weather. Tania and Robert collected hundreds of checks and bills of all denominations. Some people had clearly gone door-to-door collecting donations. Robert recalls one young woman who handed him a large, heavy envelope filled with change.

The third annual Walk for a Cure raised as much money as the previous two walks combined.

To show their appreciation, Tania and Robert had arranged for a lavish spread at their home after the walk. Scores of soggy walkers soon filled the house, eating, talking and sharing before departing amid promises to do it again.

By 11:30 p.m. Sunday, a weary

Commentary

Phase III trial of SU11248: Some questions and concerns

By Norman Scherzer

The Life Raft Group has been investigating the protocol for the forthcoming phase III clinical trial for the Sugen drug SU1248. This drug was initially developed by the Sugen Pharmaceutical drug company. Sugen was then bought by Pharmacia, which in turn was then bought by Pfizer.

This expanded clinical trial is projected to involve at least 500 GIST patients in thirty to forty medical centers, including several outside the United States. The trial will enroll GIST patients who have developed resistance to Gleevec, but unlike the earlier trials for this drug will include a randomly assigned placebo for one third of the GIST patients. The intent is to monitor this placebo group closely and to transfer those who show tumor growth into the drug treatment group. We are told that the need for a placebo is to

help document the impact of the drug because it is not expected to show as dramatic a result in shrinking tumors as did Gleevec.

In the course of our investigation we have had initial discussions with the Principal Investigator, George Demetri, and with officials at the FDA and at Pfizer.

We are attempting to address the following questions:

- When can we obtain the names of the projected sites and start dates for this clinical trial?
- At what point would Pfizer offer this drug on a compassionate use basis?
- What is the risk to the patient posed by being in the placebo group?
- Is there any alternative to using a placebo? How would that impact the speed of the research process?
- Can a placebo be implemented without the awareness of the patient and, if not, what are the consequences?

- What are the relative roles of the FDA, the drug company and the Principal Investigator, and is there any meaningful role for a patient group such as the Life Raft Group.

These are new and complex areas for us and we are trying to achieve an appropriate balance between the needs of GIST patients and of the research community.

We were reassured by a long and thoughtful dialogue with the SU11248 Development Team Leader of Pfizer which ended with an invitation to continue this discussion in a few days at Pfizer headquarters in New York City. We agreed that we needed to develop a relationship based on mutual trust and respect.

To be continued ...

Norman Scherzer is executive director of the Life Raft Group, a former disease management specialist at the Centers for Disease Control, and retired assistant commissioner of health for New York City.

DIRECTORY: Physicians are encouraged to sign up

From Page 2

be expanded to ensure widespread access of patients to physicians with expertise in treating GIST, a connection we consider vital to quality care.

Physicians can continue to sign on by going to www.liferaftgroup.org/doctor.htm. The next step will be a GIST specialist group to help doctors in third-world countries.

LIFE RAFT GROUP

NEDERLANDS IS OFFICIAL

The Netherlands Life Raft Group has officially organized itself as a formal patient group in the Netherlands. Plans are to launch a Dutch language Web site to provide information and education about GIST. Working with the

parent organization in the United States, the Dutch Life Rafter, under the leadership of Ton de Keijser, will provide a model for other Life Raft Group international chapters.

MEDICAL CONTENT SEARCH ENGINE

Visitors to the Life Raft Group Web site can now find a search engine in the medical contents section that will facilitate their research into this growing body of information.

DAS LEBENSHAUS

Our German strategic partners, Das Lebenshaus, have put out their first publication for GIST and CML. Read-

ers of German can access much of this and more at their Web site: www.daslebenshaus.org. Felix Soldan leads this new group and Life Raft Group member Ulrich Schnorf, our Swiss country representative, serves as a founding member and as a liaison to the Life Raft Group.

PATIENT ASSISTANCE PROGRAM GROWING

The number of GIST patients reaching out to the Life Raft Group office for personal assistance continues to grow. One 48-hour period this month saw seven GIST patients and family members contact our office for assis-

See ASSISTANCE, Page 6

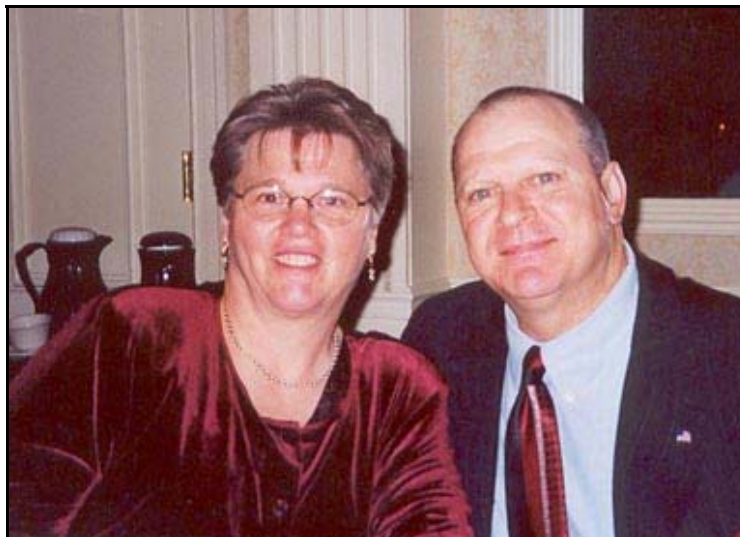
The doctor had good news and bad news

For Bonnie Girard, what was first thought to be an infection was cancer

My story starts in March of this year. I started having upper stomach pain and my stomach area was very tender to the touch. I went to my family doctor and he did X-rays, an ultrasound and a CT scan. The CT scan showed a cyst on one of my ovaries and a spot on my small intestines that they said was an infection. My doctor sent me to a gastroenterologist who put me on antibiotics for 10 days.

Later I had another CT scan and though the spot was gone, I still had the same pain and tenderness. My doctor sent me for a upper GI; nothing showed up. At this point he was puzzled as to what was the problem. So he suggested I get a colonoscopy (I'd never had one and at age 54 I was due) and said he would also do an endoscopy.

Nothing showed up on either of these. Still puzzled! The doctor suggested I see a general surgeon.



Bonnie Girard is pictured with her husband, Mike. The couple celebrated their 36th anniversary this past August.

After the colonoscopy and endoscopy, the pain only grew worse and I had to go to emergency room. They gave me a shot of pain medicine via an IV that was great!

Now, the CT scan that showed the ovarian cyst had been sent to my OB/GYN. I had already made an appointment with him for my yearly exam. He called and wanted me to have some blood work and a ultrasound done before I saw him. This was done on a Monday, and when the doctor saw my ultrasound, he said he was 99 percent sure I had ovarian cancer! He told me I

needed a complete hysterectomy ASAP. He scheduled me for surgery that Friday.

I went to see the general surgeon. If he had to do more surgery while I was open, he would be there to do it. Now, I had never had any female problems and I was still having regular periods.

I had surgery May 16, 2003. After the operation, the two doctors and the pathologist said they were 100 percent sure the tumors they removed were ovarian cancer. They told my family

See BONNIE, Page 6

WALK: 'We have just gone over \$50,000 ...'

From Page 3

Robert would e-mail the GIST Support International and the Life Raft Group lists: "We have \$43,542.50 ... with more pledges (and) matching corporate donations and money we haven't counted yet. We could come close to \$50,000."

Sponsors of the Walk for a Cure included Novartis (maker of the GIST wonder drug Gleevec), Pfizer (maker of Sugen's SU11248 for GIST), Rockland Cardiology (Tania's a cardiotech there), GIST Support International (gistsupport.org), White Plains Dodge,

Union State Bank and Daniel Rifkin, CPA.

And one other sponsor — actually, two busloads of sponsors. Thanks to sorority sister Megan Lamb, daughter of GIST patient and GSI co-founder Lee Ann Lamb, the young women of Phi Sigma Sigma from Muhlenberg College filled two buses and drove from Allentown, Penn., to Rockland Lake to join in the walk, raising more than \$5,000 in the process.

A week after the walk, Robert would post another e-mail: "We have just

gone over \$50,000 ... checks keep coming daily ... thanks for your support ... we couldn't have reached that plateau without you."

"If I had to pick my family," says Tania, "I would pick each and everyone that came to the walk. Everyone worked so hard to raise money for the walk ... it was a great feeling to be surrounded by such loving, caring people."

Adds Robert: "I never saw a better-looking bunch of sick people. God bless you all."

BONNIE: 'I feel I was one of the lucky ones ...'

From Page 5

that I probably had about five years.

The general surgeon had removed as much of the tumor around my stomach as he could. The tumor had wrapped around my intestines and he was able to unwrap it without removing any intestines.

I think it was about three days later when the doctor came into my room and said he had good news and bad news. The good news was that I did not have ovarian cancer. The bad news was I had cancer but it was GIST.

This was confirmed by testing done in Maryland. And after a couple of long weeks, the report came back that I had the protein cells and kit cells to go on Gleevec.

I have been on 400 mg. of Gleevec for a few months now and have had no side effects.

My husband says the doctors did me a big favor. They thought it was ovarian cancer, so when I had surgery they cleaned out everything they could. All that was left was small particles on my stomach lining. From reading some of the e-mails from Life Rafter's, I feel I was one of the lucky ones, as I only had to have a hysterectomy and none of my other organs were partly or to-



Bonnie Girard is seen holding her two grandchildren. Twins Gavin and Brenna were born Aug. 5 this year to her youngest son, Tim, and his wife, Erin.

tally removed.

With most of my GIST surgically removed, it cannot be detected by CT scans or MRIs. I was told they would monitor my progress with blood tests and scans to be sure the GIST does not spread. It worries me that the only way they can tell if the GIST has cleared up

is to open me up in a year or two. If the pain doesn't get as bad as it was before the operation, that would be a good sign (I guess).

Bonnie Girard is a resident of Glens Falls, nestled between the Hudson River and the Adirondack Mountain range in New York State.

ASSISTANCE: Many outside U.S. have been helped

From Page 4

tance in sorting out their treatment options and for help in navigating financial and medical access issues. Although the Life Raft Group office is not a substitute for medical specialist care, it can help guide patients through the complex issues they need to address. Our assistance in accessing treatment, particularly in other countries, continues to be quite successful.

DOSAGE AND RELAPSE

In a prior newsletter we reported on the early results of our investigation into whether there is a relationship be-

tween actual dosage (as opposed to starting dosage) and GIST patients relapsing on Gleevec. Although months have passed, we have yet to see a report of a similar investigation on the part of the clinical research community. We plan to continue this study until we accumulate enough data to draw some more definitive conclusions.

PATIENT COMPLIANCE

We are developing a protocol to confidentially interview GIST patients to determine levels of compliance with Gleevec. We have several documented

cases where the actual dosage that patients are taking is significantly different from the dosage their doctors think they are taking. This may distort the data of those in clinical trials and could adversely influence the medical care that the patient needs. Our objective is to investigate how widespread this is.

EVOLVING PATIENT DATABASE

The ability to look at issues such as dosage level and relapse, compliance and the effectiveness of new drugs is

See **DATABASE**, Page 7

Frank Weigand, 66, fought GIST 13 years

Frank Weigand of Valley Forge, Pennsylvania, lost his 13-year battle with GIST on Oct. 24. He was 66.

Born and raised in Philadelphia, Mr. Weigand held undergraduate and graduate degrees in electrical engineering from Drexel University. His career was spent in various management positions at Philadelphia Electric Company.

Mr. Weigand loved the outdoors and enjoyed hiking, camping, gardening and traveling. He was active in Rotary International and local civic activities.

He is survived by his wife, Ruth; a daughter, Susan Smith; a son, Drew Weigand, and four grandchildren who adored their “PopPop.”



Frank and Ruth Weigand of Valley Forge, Penn., U.S.A.

U of CHICAGO

From Page 2

present, the drug is far more likely to work. It is given as a continuous infusion over five days every three weeks, and is well tolerated. Deletions of 9p in GIST have been shown to correlate with more aggressive tumors, hence this drug may be able to benefit those patients who need it most.

One trial that recently filled will test BAY439006. This oral drug — a “Raf” inhibitor — targets signaling pathways downstream from c-kit. This trial includes several GIST patients.

There is also PKC787, an oral drug that inhibits c-kit and is an anti-angiogenic drug.

“We have a very large phase I (early drug development program) here at U Chicago,” says Kindler, “hence we can offer many other novel agents to our patients long before they become available to patients in other studies. We select drugs based on their mechanism of action and how this relates to the biology of GIST tumors.

“Our intention is to evaluate these drugs in GIST patients, and once it becomes evident that these drugs have activity in GIST patients, we will explore which patients it is most likely to benefit (based on the mutations in their tumors) and evaluate it in larger trials exclusively in GIST patients.

“We do not wish to merely copy the studies being done at other centers, we want to evaluate new therapies that may further advance the knowledge in this field and thus offer the greatest benefit to patients with this disease.”

Kindler also notes that a colleague, Dr. Mitchell Posner, who also has a research interest in GIST, has a great deal of experience operating on GIST patients. “Patients from other hospitals who were told that they were inoperable have successful surgeries with Dr Posner,” said Kindler.

Those interested in an appointment at the university can call the intake coordinator, Karen, at (773) 834-7424.

DATABASE

From Page 6

due to our evolving patient data base which permits us to look at issues not addressed by the traditional clinical research community and to expedite the flow of information to GIST patients and their doctors.

We are attempting to navigate the lethal time gaps that occur in the clinical research world and that, although understandable, are not acceptable to those reaching out for treatment options to stay alive.

PEDIATRIC GIST

The Life Raft will shortly begin a new initiative to address the unique issues of pediatric GIST, including forming a subgroup of patients and families and an outreach project to try to bring together medical specialists to address this issue. Pediatric GIST patients find themselves in an unusual medical limbo, being part of a rare subgroup of a rare cancer. The focus of research to date has been on adult GIST.

THE LIFE RAFT GROUP

E-mail: liferaft@liferaftgroup.org
 Internet: www.liferaftgroup.org

• 40 Galesi Drive
 • Wayne, NJ 07470

• Telephone: 973-837-9092
 • Fax: 973-837-9095

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. Many 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. Several new drugs are now in clinical trials.

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 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 articles 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, incorporated in New Jersey, U.S.A.,

Executive Director
 Administrative Assistant
 Chief Financial Officer
 IT Director
 General Counsel
 Accountant
 List Manager
 Newsletter Editor
 Science Coordinator
 Web Master
 Fund-raising co-chairmen

Norman Scherzer
Tricia McAleer
John Poss
James Roy
Thomas Overley
Roberta Gibson
Mia Byrne
Richard Palmer
Jerry Call
Gary Golnik
John Poss
Gerald Knapp

nscherzer@liferaftgroup.org
tmcaleer@liferaftgroup.org
jcpoos@swbell.net
jroy@liferaftgroup.org
guitarman335@msn.com
[dnrgibson@yahoo.com](mailto:dnrngibson@yahoo.com)
mebmcb@wowway.com
richardpalmer@hawaii.rr.com
Jerry.Call@attbi.com
liferaft@attbi.com
jcpoos@swbell.net
gsknapp@winfirst.com

Life Raft country representatives

Australia
 France
 Iran
 Mexico
 Netherlands
 Poland
 Switzerland
 United Kingdom

Greg Ladbrooke
Bertrand de la Comble
Negar Amirfarhad
Rodrigo Salas
Ton de Keijser
Bartosz Szczesny
Ulrich Schnorf
David Cook

lad57b@bigpond.com
bdelacomble@oreka.com
negaraf@sympatico.ca
rsalas@maprex.com.mx
akeijser1@chello.nl
bsz1974@yahoo.com
ulrich.schnorf@dplanet.ch
D.Cook@sheffield.ac.uk

Life Raft area groups

Chicago, U.S.A.
 Detroit, U.S.A.
 Los Angeles, U.S.A.
 New York, U.S.A.

Richard Kinzig
Alan Tobes
Floyd Pothoven
Dan Cunningham
 and **Bernie Kaplan**

rjkinz@aol.com
atobes@comcast.net
floyd@lasersealer.com
CunninghamDA@coned.com
BBKap@aol.com

Board of Directors

President
 Secretary-Treasurer
 Director
 Director
 Director
 Director

Stan Bunn
Bernie Kaplan
Gary Golnik
Mike Matthews
Rodrigo Salas
Silvia Williams

sbunn@bstsoftware.com
BBKap@aol.com
liferaft@attbi.com
mike@caster-rack.com
rsalas@webtelmex.net.mx
nswplas@mb.sympatico.ca

as a 501-c-3 nonprofit organization, are tax deductible in the United States.

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

The Life Raft Group
 40 Galesi Dr.
 Wayne, NJ 07470

Disclaimer

We are patients and caregivers, not doctors. Information shared is not a substitute for discussion with your doctor. As for the newsletter, every effort to achieve accuracy is made but we are human and errors occur. Please advise the newsletter editor of any errors.