



LIFE RAFT GROUP

December 2001

Volume 2, Number 11

Happy 'STI' holidays from Bristow America



When Life Rafter Marina Symcox was asked to submit a photo to go with her article, first posted to the Life Raft Group and reprinted on Page 3, she responded by enlisting her kids and staging this live holiday greeting. No easy feat, as the photo shoot was attempted more than once before wind and sun cooperated. Wishing Life Rafter's a Happy "STI" Holidays are Kevin ("S"), Carl ("T") and Miranda ("I") Symcox. The family lives in the small town of Bristow, Oklahoma, U.S.A., which Marina fondly refers to as "Bristow America."

Lobbying sought for Medicare reform

By Joe Stevens
Life Raft Advocacy

Iwanted to remind everyone of the Life Raft Group's efforts supporting the Access to Cancer Therapies Act of 2001.

The act, introduced in the House of Representatives as HR 1624 and in the

Senate as S 913, would extend Medicare coverage to all oral cancer drugs under Part B of Medicare. As of the beginning of this month, the bill had 237 co-sponsors in the House and 24 co-sponsors in the Senate.

Medicare now covers the cost of most cancer drug therapy because the drugs are administered through injec-

tions by providers. Since 1993, oral anti-cancer drugs have been covered only if they are available in both oral and injectable form. Gleevec, since its solely an oral drug, isn't covered.

You can show your support for HR 1624 and S 913 by calling your U.S. Representative or Senator if he or she

[See Advocate, next page](#)

Advocate

From the front page

is not a co-sponsor of the act, and request that they co-sponsor this legislation. If they are already co-sponsors, you may want to call and thank them for their support and urge them to work for passage of these bills.

I contacted my senator's office and had a lengthy conversation with a staff member regarding what to expect when scheduling a visit. Each office handles this a bit differently though generally the same. Getting to meet the senator or congresspersons is not very easy. Typically an aide who is familiar with the issue will meet with you initially.

First step is to call for an appointment at your local field office. The next step will be a return call from one of the aides or staff to schedule the appointment. That's when you can briefly discuss the issue involved.

A confirmation call before your visit with the staffer will assure that the meeting is not overlooked and the staff person is prepared.

A typical meeting will last about 30 minutes. Have copies of your statement to leave with the aide. Request a follow-up response from the senator or congressperson.

Send a follow-up note to the office for their continued support or, hopefully, future co-sponsorship of this bill.

As a group we are small in number, influence, and resources. Individually, we have powerful stories to convey regarding oral cancer treatment. That is where we can make a difference in supporting this effort.

If anyone would like more information regarding the Medicare reform campaign, or if you missed the e-mail postings regarding this issue, you can contact me directly at JBSTEVEN@harthosp.org.

Legislators who support Medicare coverage of oral cancer drugs, including Gleevec

Here are the U.S. senators and representatives currently co-sponsoring the Access to Cancer Therapies Act of 2001 (original sponsor in bold). If your senator or congressman isn't listed, you find your legislator and how to contact them at www.visi.com/juan/congress/ziptoit.html

This Web site lets users identify their federal representatives by zip code.

To track the progress of HR 1624 or S. 913, try <http://thomas.loc.gov/home/thomas.html> This Web site provides comprehensive information on legislation and its progress.

S. 913 co-sponsors:

Sen Bennett, Robert F.
Sen Bingaman, Jeff
Sen Brownback, Sam
Sen Cantwell, Maria
Sen Carper, Thomas R.
Sen Chafee, Lincoln D.
Sen Collins, Susan M.
Sen Corzine, Jon
Sen Daschle, Thomas A.
Sen DeWine, Michael
Sen Dodd, Christopher J.
Sen Dorgan, Byron L.
Sen Feinstein, Dianne
Sen Fitzgerald, Peter G.
Sen Hollings, Ernest F.
Sen Hutchinson, Tim
Sen Inhofe, James M.
Sen Johnson, Tim
Sen Kennedy, Edward M.
Sen Kerry, John F.
Sen Lieberman, Joseph I.
Sen Lincoln, Blanche
Sen Miller, Zell
Sen Roberts, Pat
Sen Rockefeller IV, John D.
Sen Sarbanes, Paul S.
Sen Smith, Gordon
Sen Snowe, Olympia
Sen Stabenow, Debbie
Sen Thomas, Craig
Sen Torricelli, Robert G.

H.R. 1624 co-sponsors:

Rep Abercrombie, Neil
Rep Ackerman, Gary L.
Rep Andrews, Robert E.
Rep Bachus, Spencer
Rep Baird, Brian
Rep Baldacci, John Elias
Rep Baldwin, Tammy
Rep Barcia, James A.
Rep Barrett, Thomas M.
Rep Barton, Joe
Rep Bass, Charles F.
Rep Bentsen, Ken
Rep Berman, Howard L.
Rep Berry, Marion
Rep Biggert, Judy
Rep Bishop, Sanford D. Jr.
Rep Blagojevich, Rod R.
Rep Blumenauer, Earl

Rep Blunt, Roy
Rep Boehlert, Sherwood L.
Rep Bonilla, Henry
Rep Bonior, David E.
Rep Borski, Robert A.
Rep Brady, Kevin
Rep Brady, Robert
Rep Brown, Sherrod
Rep Bryant, Ed
Rep Burton, Dan
Rep Callahan, Sonny
Rep Camp, Dave
Rep Cannon, Chris
Rep Cantor, Eric
Rep Capito, Shelley Moore
Rep Capps, Lois
Rep Capuano, Michael E.
Rep Carson, Brad
Rep Carson, Julia
Rep Castle, Michael N.
Rep Christensen, Donna M.
Rep Clay, Wm. Lacy
Rep Costello, Jerry F.
Rep Coyne, William J.
Rep Cramer, Robert E. Jr.
Rep Crenshaw, Ander
Rep Crowley, Joseph
Rep Cubin, Barbara
Rep Cummings, Elijah E.
Rep Cunningham, Randy
Rep Davis, Danny K.
Rep Davis, Jo Ann
Rep DeFazio, Peter A.
Rep DeLauro, Rosa L.
Rep DeMint, Jim
Rep Deutsch, Peter
Rep Dicks, Norman D.
Rep Doolittle, John T.
Rep Doyle, Michael F.
Rep Duncan, John J. Jr.
Rep Dunn, Jennifer
Rep Edwards, Chet
Rep Ehrlich, Robert L. Jr.
Rep Emerson, Jo Ann
Rep Engel, Eliot L.
Rep Eshoo, Anna G.
Rep Etheridge, Bob
Rep Evans, Lane
Rep Farr, Sam
Rep Ferguson, Mike
Rep Filner, Bob
Rep Foley, Mark

Rep Frank, Barney
Rep Frelinghuysen, Rodney P.
Rep Frost, Martin
Rep Gallegly, Elton
Rep Gekas, George W.
Rep Gilchrest, Wayne T.
Rep Gilman, Benjamin A.
Rep Gonzalez, Charles A.
Rep Goode, Virgil H. Jr.
Rep Goodlatte, Bob
Rep Gordon, Bart
Rep Green, Gene
Rep Greenwood, James C.
Rep Grucci, Felix J. Jr.
Rep Gutierrez, Luis V.
Rep Hall, Tony P.
Rep Hart, Melissa A.
Rep Hastings, Alcee L.
Rep Hayworth, J. D.
Rep Hefley, Joel
Rep Hinchey, Maurice D.
Rep Hobson, David L.
Rep Honda, Michael M.
Rep Hooley, Darlene
Rep Horn, Stephen
Rep Houghton, Amo
Rep Hunter, Duncan
Rep Hutchinson, Asa
Rep Hyde, Henry J.
Rep Inslee, Jay
Rep Isakson, Johnny
Rep Jackson, Jesse L. Jr.
Rep Jackson-Lee, Sheila
Rep Jefferson, William J.
Rep Johnson, Eddie Bernice
Rep Jones, Stephanie Tubbs
Rep Jones, Walter B. Jr.
Rep Kaptur, Marcy
Rep Keller, Ric
Rep Kelly, Sue W.
Rep Kennedy, Patrick J.
Rep Kerns, Brian D.
Rep Kildee, Dale E.
Rep King, Peter T.
Rep Kirk, Mark Steven
Rep Knollenberg, Joe
Rep Kolbe, Jim
Rep LaFalce, John J.
Rep LaHood, Ray
Rep Lantos, Tom

A tale of five Decembers

Editor's note: Marina Symcox posted this to the Life Raft Group and to ACOR's leiomyosarcoma support list 10 days before Christmas. It's worth sharing with those who haven't seen it. It's even worth reading again, at this most hopeful of seasons.

By Marina Symcox

December 15, 1997: In the hospital, recuperating from a gastrointestinal resection, and terrified from the news that I have three to five months to live due to metastatic liver tumors.

December 15, 1998: I'm in the midst of a 10-day continuous infusion of DTIC ... ambulatory pump, ice packs, Zofran.

December 15, 1999: I am bedridden for the most part, and two months away from enrolling in hospice.

December 15, 2000: I am bedridden for the most part, but tumors are rapidly shrinking from Gleevec.

December 15, 2001: I swallow my morning dose of Gleevec and prepare for the big day. I attend my daughter's piano recital at Advent Christian Church, in Bristow America. Performers range from kindergarteners to 6th graders. My own daughter wears a blue velvet pant suit and black plastic slip-on shoes, high heeled, textured to simulate suede, and trimmed in rhinestones. I notice another child is wearing the same shoes. I notice most of the little girls are wearing holiday velvet outfits that I recognize from the racks at Wal-Mart. (In Bristow America, shopping is either the boutique Wal-Mart or a 40-minute drive to the malls in Tulsa.)

Most children haven't practiced their pieces nearly enough. My own daughter has a natural ability for singing on pitch. She amazes the crowd with her



This photo was taken in April 2000, six months after Marina Symcox started Gleevec and six months after she left hospice. She and her 10-year-old son, Carl, are celebrating at the finish line of the first Oklahoma City Marathon, in front of the Oklahoma Capitol. The marathon was organized to honor the victims of the bombing of the Alfred P. Murrah Federal Building. The theme: Celebration of Life. Marina walked a three-mile leg as one of a four-person relay team. Teammates, not shown, ran the remaining 23 miles of the marathon.

rendition of "Jolly Old St. Nicholas" and "Good King Wenceslas," playing from one of those "big-easy-one-note-at-a-time" piano books, and singing brightly and energetically into the microphone, and of course with perfect pitch.

Victoria, from down the street, struggles with "Away in the Manger." Her parents, sitting behind me, hope that Victoria has learned a lesson about not practicing as she should.

The high performance of the afternoon, is offered by Hannah the kindergartener ... shorter and plumper than most 5-year-olds ... wearing a pink satin tea length dress ... not from Wal-Mart, but perhaps a leftover flower-girl dress from a spring wedding. Hannah sings "Silent Night," sometimes on pitch, but sometimes not ... that "sleep in heavenly peeeace" section of the song is enough to strain even the most experienced vocal chords. Hannah wins the day with the biggest

smile, and the least inhibition about singing off-key.

Some of the worst music I have ever heard, and one of the best December 15ths that I have ever had.

Postscript December 16, 2001: *I have a middle school band concert this afternoon, in the high school gym. I can't wait to go, but don't believe they can out-perform Hannah in her satin pink dress.*

A week ago the middle school band marched in the Bristow Christmas parade. The band was right behind the group of Harley-Davidson motorcycles decorated in battery powered Christmas lights and driven by the tattooed, leather-clad, bearded types that you normally associate with Harley-Davidson motorcycles. As you might imagine, 30 middle schoolers on clarinet and trumpet can't compete with the sound level of a dozen Harleys.

I never laughed so hard.

Who's new in the Life Raft Group

Maryann Klein, on the trial at Dana-Farber Cancer Institute in Boston, Mass., U.S.A.

Georgia and **Bob Caraway** of Denton, Texas, U.S.A. Bob is in the trial at M.D. Anderson Cancer Center in Houston, Texas, U.S.A.

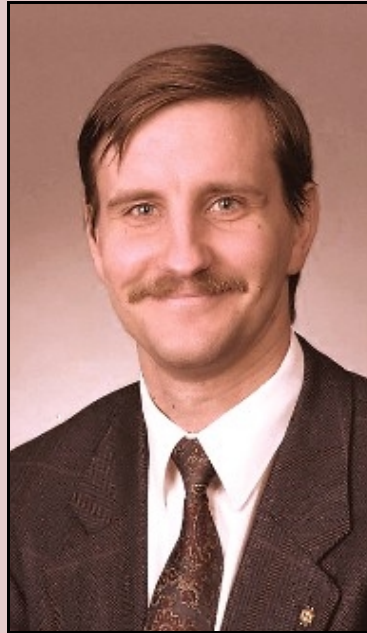
Susan Karp, New York City, U.S.A., by prescription.

Diane and **Robert Lecca** of California. Robert is on prescription from doctors at the University of Southern California., U.S.A.

Dan Hoffman of Mechanicsburg, Penn., U.S.A., on the trial at Washington Cancer Institute.

And, with apologies for misspelling his first name last month:

Tuomas Hemminki of Vaasa, Finland, on the trial in Helsinki



Tuomas Hemminki of Vaasa, Finland, started Glivec (as it's known outside the U.S.) last February. A university administrator, Tuomas is active in the Junior Chamber International

Supporters

From Page 2

Rep Latham, Tom
Rep LaTourette, Steve C.
Rep Leach, James A.
Rep Lee, Barbara
Rep Levin, Sander M.
Rep Lipinski, William O.
Rep LoBiondo, Frank A.
Rep Lowey, Nita M.
Rep Lucas, Frank D.
Rep Lucas, Ken
Rep Luther, Bill
Rep Maloney, Carolyn B.
Rep Maloney, James H.
Rep Manzullo, Donald A.
Rep Matheson, Jim
Rep Matsui, Robert T.
Rep McCarthy, Carolyn
Rep McCollum, Betty
Rep McDermott, Jim
Rep McGovern, James P.
Rep McIntyre, Mike
Rep McNulty, Michael R.
Rep Meehan, Martin T.
Rep Meek, Carrie P.
Rep Mica, John L.
Rep Millender-McDonald, Juanita
Rep Miller, George
Rep Mink, Patsy T.
Rep Moore, Dennis
Rep Moran, James P.

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Life Rafterers meet in NYC



Ronna Lindeken and Dan Cunningham got together in New York City in August to share some of their GIST/Life Raft experiences. Ronna's boyfriend, Bob, took this photo outside a restaurant on the upper East Side. "Although we never met before, our common bond prompted a personal and rewarding conversation," says Dan.

Meeting of minds at Dana-Farber

Life Raft Group Coordinator Norman Scherzer and Gilles Frydman, president of the Association of Online Resources, traveled to Dana-Farber Cancer Institute in Boston on Thursday, Dec. 13, to meet with Dr. George Demetri, medical director of the Center for Sarcoma and Bone Oncology.

Building upon many months of e-mail and telephone interchanges, they met for more than four hours to discuss how to better respond to the needs of GIST patients and their doctors and nurses.

A major focus of the discussion was the feasibility of creating a non-profit organization to educate doctors and nurses about GIST, Gleevec and other new kinase inhibitors.

Also explored was the possibility of expanding upon the unique patient-driven data base created by the Life Raft Group. The day's discussions



Posing for this photo after their meeting Dec. 13 at Dana-Farber Cancer Institute were, from left, Dr. George Demetri, Life Raft Group Coordinator Norman Scherzer, Dr. Edward Benz, president of Dana-Farber, and Gilles Frydman, president of the Association of Online Cancer Resources.

were far ranging and also included a number of clinical and research areas.

The day concluded with a meeting with Dr. Edward Benz, the president of Dana-Farber. Benz was quite inter-

ested in the potential collaborations being explored and, like many other Dana-Farber staff encountered during the day, very aware of the work done by ACOR and by the Life Raft Group.

Supporters II

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|-------------------------------|-------------------------------|---------------------------|---------------------------|--------------------------|
| Rep Moran, Jerry | Rep Phelps, David D. | Rep Roukema, Marge | Rep Smith, Adam | Rep Udall, Tom |
| Rep Morella, Constance A. | Rep Pickering, Charles (Chip) | Rep Rush, Bobby L. | Rep Smith, Christopher H. | Rep Walden, Greg |
| Rep Myrick, Sue | Rep Platts, Todd Russell | Rep Ryan, Paul | Rep Snyder, Vic | Rep Walsh, James T. |
| Rep Nadler, Jerrold | Rep Pomeroy, Earl | Rep Ryun, Jim | Rep Souder, Mark E. | Rep Watkins, Wes |
| Rep Napolitano, Grace F. | Rep Portman, Rob | Rep Sabo, Martin Olav | Rep Spence, Floyd | Rep Watson, Diane E. |
| Rep Neal, Richard E. | Rep Price, David E. | Rep Sanchez, Loretta | Rep Stearns, Cliff | Rep Watt, Melvin L. |
| Rep Nethercutt, George R. Jr. | Rep Pryce, Deborah | Rep Sawyer, Tom | Rep Strickland, Ted | Rep Weiner, Anthony D. |
| Rep Ney, Robert W. | Rep Putnam, Adam H. | Rep Saxton, Jim | Rep Stump, Bob | Rep Weldon, Curt |
| Rep Norton, Eleanor Holmes | Rep Quinn, Jack | Rep Schakowsky, Janice D. | Rep Stupak, Bart | Rep Weldon, Dave |
| Rep Oberstar, James L. | Rep Ramstad, Jim | Rep Schiff, Adam B. | Rep Sununu, John E. | Rep Weller, Jerry |
| Rep Olver, John W. | Rep Rangel, Charles B. | Rep Schrock, Edward L. | Rep Sweeney, John E. | Rep Wexler, Robert |
| Rep Owens, Major R. | Rep Regula, Ralph | Rep Scott, Robert C. | Rep Tanner, John S. | Rep Wicker, Roger F. |
| Rep Pallone, Frank Jr. | Rep Rehberg, Dennis R. | Rep Serrano, Jose E. | Rep Thompson, Bennie G. | Rep Wolf, Frank R. |
| Rep Pascrell, Bill Jr. | Rep Riley, Bob | Rep Sessions, Pete | Rep Thompson, Mike | Rep Woolsey, Lynn C. |
| Rep Pelosi, Nancy | Rep Rivers, Lynn N. | Rep Shaw, E. Clay, Jr. | Rep Tiahrt, Todd | Rep Wu, David |
| Rep Peterson, Collin C. | Rep Rogers, Mike | Rep Sherwood, Don | Rep Tiberi, Patrick J. | Rep Wynn, Albert Russell |
| Rep Peterson, John E. | Rep Ros-Lehtinen, Ileana | Rep Shows, Ronnie | Rep Tierney, John F. | Rep Young, Don |
| Rep Petri, Thomas E. | | Rep Simmons, Rob | Rep Towns, Edolphus | |

THE LIFE RAFT GROUP

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Who are we and what do we do? We started as GIST patients and caregivers (spouses and others) in the Gleevec (STI571) clinical trials, and have since extended membership to all GIST patients on Gleevec/Glivec. We come together to share our experiences and support each other. We focus on symptoms, side effects and other drug-related issues. Members correspond privately to each other and to the group as appropriate.

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. To assist in that goal, the secure e-mail listserv does not include professional members of the various study sites. However, this newsletter does serve as an out-

reach and is widely distributed. Hence, all items in the newsletter are edited to maintain the anonymity of members, unless members have granted publication of more detailed information.

Method: Our primary means of communication is through a confidential, secure listserv operated by the Association of Cancer Online Resources, ACOR (www.acor.org).

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

Newsletter note: 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 you may find.

In Memoriam

There have been eight deaths of Life Raft Members 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, 16, and Scott, 9.
- **Ron Martinez**, 60, July 2, 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.

Life Raft member Bruce Walter Gunn, 43

Bruce Walter Gunn died Thursday, November 8, 2001, at home in Watsonville, California, U.S.A.

A native of Palo Alto, Mr. Gunn graduated from Gunn High School, named after his grandfather Henry M. Gunn, in 1976. He earned a bachelor's degree in forest management from Humboldt State University in Arcata, California in 1983.

He served with his wife as a Peace Corps volunteer in Honduras from 1987-89, where he implemented the first operative plan for Calaque National Park, the tallest mountain in Honduras. He refurbished an antiquated hydroelectric plant into a park visitor center there, which was later named for him.

Mr. Gunn owned and operated Gunn Construction since 1992. He also worked as a construction supervisor and superintendent for South County Housing since 1996. He loved spending time in the outdoors hiking, snorkeling, fishing, and bike riding.

Mr. Gunn is survived by his wife of 18 years, Roisin; three sons, Seamus, Liam and Brendan, all of Watsonville; a daughter, Aislinn, of Watsonville; two sisters, Mari Kauffman of Colorado and Lara Fisher of Aptos, California; his parents Jack and Sue Gunn of Hawaii; and an aunt Ruth Gunn Mota of Watsonville.

A memorial Mass was said Nov. 12 at Holy Eucharist Catholic Church. Cremation services have been arranged by Mehl's Colonial Chapel.