I wanted 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 injections 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

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 Rafters 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.”
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 congressmember isn’t listed, you find your legislator and how to contact them at [www.visi.com/juan/congress/ziptoit.html](http://www.visi.com/juan/congress/ziptoit.html).

**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 DeWeine, 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

**S. 913 co-sponsors:**
- Sen Snowe, Olympia
  - Sen Stabenow, Debbie
  - Sen Thomas, Craig
  - Sen Torricelli, Robert G.
- 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, Sherrrd
- 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 Fringlehuyse, Rodney P.
- Rep Frost, Martin
- Rep Gallegly, Elton
- Rep Geakas, George W.
- Rep Gilchrest, Wayne T.
- Rep Gilman, Benjamin A.
- Rep Gonzalez, Charles A.
- 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 Iasaki, Johnny
- Rep Jackson, Jesse L. Jr.
- Rep Jackson-Lee, Sheila
- Rep Jefferson, William J.
- Rep Johnson, Eddie Bernice
- Rep Jones, Stephanie Tubbs
- Rep Kaptur, Marcy
- Rep Keller, Ric
- Rep Kelly, Sue W.
- Rep Kennedy, Patrick J.
- Rep Kerns, Brian D.
- Rep Kiddee, 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

[See Supporters, Page 4]
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 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 kindergartner ... 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 peace” 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.

See Supporters II, Page 5

Life Rafters 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 possibly of expanding upon the unique patient-driven data base created by the Life Raft Group. The day’s discussions 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 interested 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.

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.

Supporters II
From Page 4

Rep Moran, Jerry
Rep Morella, Constance A.
Rep Myrick, Sue
Rep Nadler, Jerrold
Rep Napolitano, Grace F.
Rep Neal, Richard E.
Rep Nethercutt, George R. Jr.
Rep Ney, Robert W.
Rep Norton, Eleanor Holmes
Rep Oberstar, James L.
Rep Olver, John W.
Rep Owens, Major R.
Rep Pallone, Frank Jr.
Rep Pascrell, Bill Jr.
Rep Pelosi, Nancy
Rep Peterson, Collin C.
Rep Peterson, John E.
Rep Petri, Thomas E.
Rep Phelps, David D.
Rep Pickering, Charles (Chip)
Rep Platts, Todd Russell
Rep Pomeroy, Earl
Rep Portman, Rob
Rep Price, David E.
Rep Pryce, Deborah
Rep Putnam, Adam H.
Rep Quinn, Jack
Rep Ramstad, Jim
Rep Rangel, Charles B.
Rep Regula, Ralph
Rep Rehberg, Dennis R.
Rep Riley, Bob
Rep Rivers, Lynn N.
Rep Rogers, Mike
Rep Ros-Lehtinen, Ileana
Rep Roukema, Marge
Rep Rush, Bobby L.
Rep Ryan, Paul
Rep Ryun, Jim
Rep Sabo, Martin Olav
Rep Sanchez, Loretta
Rep Sawyer, Tom
Rep Saxton, Jim
Rep Schakowsky, Janice D.
Rep Schiff, Adam B.
Rep Schrock, Edward L.
Rep Scott, Robert C.
Rep Serrano, Jose E.
Rep Sessions, Pete
Rep Shaw, E. Clay, Jr.
Rep Sherwood, Don
Rep Shows, Ronnie
Rep Simmons, Rob
Rep Smith, Adam
Rep Smith, Christopher H.
Rep Snyder, Vic
Rep Souder, Mark E.
Rep Spence, Floyd
Rep Stearns, Cliff
Rep Strickland, Ted
Rep Stump, Bob
Rep Stupak, Bart
Rep Sununu, John E.
Rep Tanner, John S.
Rep Thompson, Bennie G.
Rep Thompson, Mike
Rep Tiahrt, Todd
Rep Tiberi, Patrick J.
Rep Tierney, John F.
Rep Towns, Edolphus
Rep Udall, Tom
Rep Walden, Greg
Rep Walsh, James T.
Rep Watkins, Wes
Rep Watson, Diane E.
Rep Watt, Melvin L.
Rep Weiner, Anthony D.
Rep Weldon, Curt
Rep Weldon, Dave
Rep Weller, Jerry
Rep Wexler, Robert
Rep Wicker, Roger F.
Rep Wolf, Frank R.
Rep Woolsey, Lynn C.
Rep Wu, David
Rep Wynn, Albert Russell
Rep Young, Don
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 listserve does not include professional members of the various study sites. However, this newsletter does serve as an outreach 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:

- **Amy Barney**, 25, June 10, 2001, wife to Reed, mother of Joshua.
- **Bruce Gunn**, 43, Nov. 8, 2001, husband to Roisin, father of Seamus, Liam, Brendan and Aislinn.

Life Raft member
Brucce 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.