

The SynCure Report – Fall 2008

Published by the SynCure Cancer Research Foundation

SynCure: A Leader in Patient Education

Since the very first public cancer education program in New York City in February 2003, SynCure has become a national leader in delivering FREE, high quality symposia for cancer patients, survivors, family members, caregivers, healthcare support personnel, patient advocates, and the general public. Sixteen programs have been held or are planned in the past five and a half years in 7 cities in Florida, Illinois, New York, and New Jersey with audiences ranging from 150 to 330. In many cases, SynCure has partnered with others to deliver these programs; special recognition goes to Holy Cross Hospital in Ft. Lauderdale (six programs) and the Leukemia & Lymphoma Society (three programs). Several aspects of the programs make them unique, including the breadth and depth of the presentations by leading cancer experts and the chance for the audience to direct questions to the speakers on any topic.



The speaker list for SynCure's educational programs (see below) is strong evidence of the quality of the programs—and all of these specialists have donated their time and expertise at no cost because of their commitment to patients. Another measure of the quality of the programs is the large number of sponsors. Many pharmaceutical and other healthcare companies, along with local businesses, have made numerous grants to SynCure to allow us to offer the programs for FREE. Finally, the comments of attendees provided in evaluation forms gives the strongest testimony (see Page 2) of the value of SynCure's programs. SynCure plans to continue its focus on patient education in the foreseeable future.

EDUCATIONAL PROGRAM SPEAKERS

National Cancer Institute, Bethesda, MD

Jennifer Eng-Wong, MD, MPH
Anne Washburn, MPH; John Morris, MD
Martin Gutierrez, MD; Philip Arlen, MD
J. Carl Barrett, PhD; John Janik, MD
JoAnne Zujewski, MD; James Guley, MD
Jennifer Low, MD; Richard Little, MD
Margaret Mooney, MD

Moffitt Cancer Center, Tampa, FL

Adam I. Riker, MD; Zainab Ilahi, MD
David S. Craig, PharmD
Tyron Hoover, MD, JD

Harvard/Dana-Farber Cancer Inst., Boston, MA

J. Paul Eder, MD
Leonard J. Appleman, MD

Cancer Institute of New Jersey, NJ

Roger Strair, MD, PhD

University of Chicago Hospitals and Health System, IL

Michael J. Hall, MD

Vanderbilt-Ingram Cancer Center Nashville, TN

Anne Washburn, MPH

Fox Chase Cancer Center, Philadelphia, PA

Michael J. Hall, MD

Memorial Sloan-Kettering CC, New York, NY

Teresa A. Gilewski, MD
Carol Portlock, MD
Jedd Wolchok, MD
Murray Brennan, MD
David W. Kissane, MD
Richard Glassman, LCSW
Carma Bylund, PhD

Columbia Presbyterian Medical Ctr, New York, NY

Howard Kaufman, MD
Emina Huang, MD
Brett Taback, MD
Jon Levenson, MD
Michael Schuster, MD

M. D. Anderson Cancer Center, Houston, TX

Luis Camacho, MD
Banu Arun, MD

Mayo Clinic, Jacksonville, FL

George Kim, MD

University of North Carolina, Chapel Hill, NC

Holly Hough, PhD

Hackensack University CC, Hackensack, NJ

Scott D. Rowley, MD

Progress in Translational Research



Last year, SynCure made research grants to two early-career investigators at leading cancer research centers to help turn promising laboratory research into new cancer therapies.

A grant was awarded to support the work of Kimberly Stegmaier, M.D., Assistant Professor of Pediatrics at Harvard Medical School and Investigator at Dana-Farber Cancer Institute in Boston, Massachusetts. Dr. Stegmaier is using the grant to search for new drugs to treat T-cell acute lymphoblastic leukemia. She recently presented a paper on her research results to date, "Modulating Notch1 with Signature-based Small Molecule Library Screening" at the European Hematology Association Meeting in Copenhagen, Denmark, June 15, 2008. She expects to have additional findings ready for publication soon.

The second grant supports the research of Gabriela Chiosis, Ph.D., in the Department of Pharmacology and Chemistry at Memorial Sloan-Kettering Cancer Center (MSKCC) in New York City. Dr. Chiosis' research focuses on developing new drugs that target a specific molecule important to the progression of small cell lung cancer. Dr. Chiosis has published 2 papers acknowledging SynCure's support. One appeared in the July 2007 issue of Nature Chemical Biology and the second in Expert Opinion on Drug Discovery, January 2008.

Five-Year Anniversary UPDATE Program Holy Cross Hospital, Ft. Lauderdale



March 29, 2008, was the date of the 5th consecutive annual **UPATE: Cancer Research and Treatment** symposium hosted jointly by SynCure and the Bienes Cancer Center at Holy Cross Hospital in Ft. Lauderdale, FL.

Over this period, the program has served more than one thousand cancer patients/survivors and their loved ones in the greater Ft. Lauderdale area; some participants have come from as far as 150 miles away. Much of the credit for the success of this long-running program goes to **Maureen Mann**, the enthusiastic and energetic Director of the Bienes Cancer Center. In addressing the audience at the most recent program, Mrs. Mann said "It seems like yesterday when we held our first program in February of 2004. I am so proud that by teaming with SynCure, we have been able to bring some of the finest cancer experts in the world to share their knowledge and insights with the people of this area." The evaluation forms completed upon the conclusion of this fifth-anniversary program requested a numeric rating for the symposium on a scale of 1-5, (5 being the best). The average score given was 4.8. Naturally, the credit for this great evaluation goes to the outstanding speakers. The 6th consecutive UPDATE program at Holy Cross is scheduled for Saturday, Feb. 7, 2009.



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Upcoming Education Programs

A new program titled **Living with Cancer: From Diagnosis to Survivor** is scheduled at the Grand Summit Hotel, **Summit, NJ** on Saturday, **November 15, 2008**, from 9:00 am to 12:45 pm. The program is co-hosted by the Leukemia and Lymphoma Society and will feature speakers from the National Cancer Institute, Hackensack University Medical Center, Columbia University Medical Center, Fox Chase Cancer Center and Memorial Sloan-Kettering Cancer Center.

February 7, 2009, is the date for the 6th Annual **UPDATE 2009: Cancer Research and Treatment** program at Holy Cross Hospital in **Ft. Lauderdale, FL**. The first five years have seen participants of 150-330 each; therefore, we expect another packed house this coming year.

Please check our website (www.syncure.org) to register for any of the programs or you can call us at 1-866-SYNCURE to register.

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EDUCATIONAL PROGRAM SPEAKERS

Holy Cross Hospital & Others, Ft. Lauderdale, FL

Nadia Ramdin, MD
Marshal Lieberfarb, MD
Carl Tahn, MD
Armand Katz, MD
Sam Das, MD
Martin Gutierrez, MD
John Kotler, MD
Dax Kurbegov, MD
Carol Brudenell, RN
Fred Dagleish, MD
Abdon Medina, MD
Ena Segota, MD
Jonathan S. Levine, MD, FACS
Allan Ribbler, PhD
Englewood Hospital & Medical Center & Others, Englewood, NJ
Jill Morrison, MD
Richard Lee, MD
Mei Zhang, MD

Tallahassee Memorial Hospital & Others, Tallahassee, FL

Alfredo Paredes, MD
Larry Harper, MD
Patrick Murrah, MD
Tim Broeseker, MD
Marie Amanze, MD
Carlos Campo, MD
John McBroom, MD
Tim Bolek, MD
Hardeep Singh, MD
Jim Stockwell, MD
James S. Killius, MD
Maribel Lockwood, MD
Centegra Sage Cancer Center & Others, McHenry, IL
Geoffrey Smoron, MD
Terrence J. Bugno, MD
Spiridon Gerolimatos, MD
Aslam S. Zahir, MD
Michael B. Soble, MD

What our attendees have to say.....



"My overall rating is a 5 (out of 5) – excellent, high quality program!!"

"The program was very interesting and the speakers were all great. It really made me aware of communication with my doctors."

"A wonderful program educating and reassuring patients. Each program is even better than the last; this is my 4th program."

"This is the 1st time that I have attended one of your programs. It was 200% greater than I expected."

"Very professional and communicated in an easy-to-understand language. The handouts of the topics to be covered are a great help."

"This is my 1st time – I think it is crucial for everyone to attend – the level of knowledge is great! The doctors were great in explaining the different cancers and types of treatments."

"The comprehensive approach to the entire road from diagnosis to end-of-life gave me (a parent of a cancer patient) a lot of help."

"The presenters were extremely competent and brought a human element to the program. Each aspect of the physician-patient relationship was touched upon."

Research Grant made to Memorial Sloan-Kettering

Steve Roman, Advisor to the SynCure Board, presented a research grant to Murray F. Brennan, M.D., at Memorial Sloan-Kettering Cancer Center in New York City. The grant was made possible by the generosity of the many participants in the Spring Classic Sporting Clays Shoot held April 27, 2008 at the Orvis Sandanona Shooting Grounds in Millbrook, NY.

The Informed Cancer Patient A Highly Regarded Program!



On November 3, 2007 at the Crowne Plaza Hotel in Englewood, NJ, SynCure and the Leukemia and Lymphoma Society hosted their second annual symposium "The Informed Cancer Patient" to provide cancer patients/survivors and their loved ones not only

information on the latest advances in cancer treatment, but also advice on how to deal with the physical, psychological and social consequences following diagnosis and treatment for cancer. As one participant commented: *"I really got a lot out of the practical, hands-on advice about being informed and proactive. I especially liked the information about living as a cancer survivor."*

The SynCure Spring Classic 2008 Orvis Sandanona Shooting Grounds



The SynCure Cancer Research Foundation held their 5th Annual 'Spring Classic' sporting clays shoot on Sunday, April 27th at the historic Orvis Sandanona Shooting Grounds in Millbrook, NY. The sold-out event attracted shooters from New York, New Jersey, Connecticut, Florida, and Rhode Island. Everyone had a terrific day

in support of an important cause. The money raised provided a research grant to Memorial Sloan-Kettering Cancer Center and will support other SynCure cancer research programs.

Firefighters Supporting Cancer Research Green Village Volunteer Fire Dept., New Jersey

On **Sunday, October 19, 2008**, the Green Village Volunteer Fire Dept. (NJ) will be conducting a sporting clays fun shoot in support of SynCure's research

initiatives. This annual event has become a 'must do' for New Jersey's shotgunners and has been a sell out for the past four years. This event has received extraordinary support from sponsors throughout the



region who have been extremely generous in providing prizes and trophies. The event has led to the formation of many solid friendships between the firefighters and the SynCure staff. SynCure is extremely grateful to these brave, courageous and dedicated volunteer firefighters.

For Your Information

On May 21st, the Genetic Information Nondiscrimination Act of 2008 (GINA) was signed into law by the President. GINA provides the following:

- Insurance companies are prohibited from denying coverage or raising premiums based upon an individual's genetic information.
- Employers are prohibited from using genetic information for making decisions about hiring, termination, promotion or assignment.
- Employers and insurance companies are prohibited from requiring that an individual submit to genetic testing.

GINA will become effective for insurance companies in May 2009 and for employers in November 2009.

The Caroline Pryce Walker Conquer Childhood Cancer Act was signed into law in July providing for a dedicated expenditure of \$30 million annually for five years commencing in 2009. This act has several objectives including:

- Supporting biomedical research on pediatric cancers.
- Enhancing a collaborative effort on clinical trials.
- Funding, via the National Institutes of Health, a fellowship program for scientists researching pediatric cancers.
- Fostering an effective public education effort on childhood cancers.

The American Society of Clinical Oncology has identified the key factors governing anxiety in cancer patients and developed guidelines for coping with treatment fears. A summary of some of the suggestions are:

- Identify and express the fear; express those fears to caregivers and medical professionals.
- Emotional well-being is based upon open communication; talk with the treatment team members.
- Develop a pre-treatment plan for managing possible side effects; forewarned is forearmed.
- Ask questions; no question is 'silly'. We tend to fear the unknown.
- Be proactive; being involved in the treatment plan is vital.
- Being frustrated or sad during treatment is normal.
- Speaking with others who have gone through the same treatment is often extremely valuable.
- Thinking about the possible long-term consequences of treatment can increase anxiety; therefore, seek out detailed information and reliable resources about the treatment's effects.
- Focus on the present; investigate relaxation techniques including meditation, yoga, focused breathing, biofeedback, music therapy, etc.

For more information on this and many other important cancer topics visit www.cancer.net.



PLEASE MAIL VOLUNTEER FORM TO:

Stephen Roman
SynCure Cancer Research Foundation
P.O. Box 1803
West Caldwell, NJ 07007

OR FAX TO: (850) 558-0364



**YES, I want to make a difference....
I want to become a SynCure volunteer by:**

- Volunteering to help develop and conduct public education programs.
- Helping to organize and conduct fundraising events (e.g., Golf Tournaments)

I believe my talents and experience would be beneficial in the following area(s):

- Advertising/Promotion/Marketing/Public Relations
- Planning/Scheduling/Coordination
- Finance
- Other (please describe) _____

Name: _____ Street: _____

City: _____ State: _____ Zip: _____

Phone: _____ Email: _____



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