



FAPTP FOOTNOTES

Summer 2012
A Quarterly Newsletter

- All Children's Hospital
- Baptist Children's Hospital
- Children's Center for Cancer & Blood Diseases at Florida Hospital Cancer Institute
- Children's Hospital at Palms West
- Children's Hospital at St. Mary's Medical Center
- Children's Hospital of SW Florida at Lee Memorial Health System
- Chris Evert Children's Hospital at Broward Health
- Joe DiMaggio Children's Hospital at Memorial
- Miami Children's Hospital
- M.D. Anderson Cancer Center-Orlando
- Nemours Children's Clinic-Jacksonville
- Nemours Children's Clinic-Orlando
- Nemours Children's Clinic-Pensacola
- St. Joseph's Children's Hospital of Tampa
- UF & Shands
- University of Miami/Jackson Memorial Medical Center

Seminar Highlights

The Florida Association of Pediatric Tumor Programs, Inc. (FAPTP)'s 34th annual seminar, *Advances in Pediatric Hematology/Oncology* was held on November 17-19, 2011 at the TradeWinds Island Grand Resort in St. Pete Beach, Florida. The seminar was a great success with attendees participating from all over the United States.



This year's seminar Medical and Nursing Directors, **Dr. William Slayton** and Hematology/Oncology Nurse, **Cathy Stegall, RN, BSN, OCN** came from University of Florida & Shands, Gainesville, Florida. They both did a superb job and FAPTP wants to take this opportunity to thank them for donating their valuable time and expertise.

FAPTP would also like to thank all of the wonderful presenters that helped to make this year's event successful.

The seminar kicked off with author and keynote speaker, **Janie Walters, MS**, from Champion Communications in Madison, Mississippi. Ms. Walters spoke about *Booster Shots for the Medical Soul*, reminding the attendees about the history of nursing and the philosophical foundations for the science of care.



Michelle Witkop, FNP-BC, DNP, ACHPN from Munson Hospital in Traverse City, Michigan, spoke to us next on the *The Long Road to Diagnosis: von Willebrand Disease and Beyond*.

Next we heard from **Hector Rodriguez-Cortes, MD**, pediatric hematologist/oncologist from Chris Evert Children's Hospital at Broward Health in Ft. Lauderdale, Florida. Dr. Rodriguez-Cortes spoke on the *General Aspects of Aplastic Anemia in Children* and also moderated a lively game of *Jeopardy, Name that Disease*, testing the attendees medical knowledge.



Following Dr. Rodriguez-Cortes' presentation, **Judith Simms-Cendan, MD**, with the UCF College of Medicine in Orlando, Florida, spoke on *Menorrhagia and Dysfunctional Uterine Bleeding in Adolescents*.

Look Inside...

- 6. News from the Centers
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- 8. 35th Annual Seminar Save the Date

Seminar Highlights



Starting up the Oncology Session was **Gregory Hale, MD**, Medical Director from All Children's Hospital, in St. Petersburg, Florida. His presentation was titled, *Hot Topics in Nursing Care of the Transplant Patient*.

The final presentation for the day came from **Melissa Kennell, DDS**, from Children's Dentistry of the Lakes Region, Gilford, New Hampshire. She spoke on *Dental Management for Patients with Hereditary Bleeding Disorders*.



We then heard from **Robert Lavey, MD**, from the H. Lee Moffitt Cancer Center & Research Institute, in Tampa, Florida. Dr. Lavey spoke on *Radiation Therapy in Children*.



Our final day of the seminar began with a presentation from **Joan O'Hanlon Curry, RN, MS, CPNP, CPON**, (picture not available) from Children's Hospital at Montefiore, Bronx, New York. Ms. O'Hanlon Curry's talk was titled, *I Can Eat that When? Neutropenic Diet: The Who, What, Where, When and Why?*

Again, **Dr. Gregory Hale**, presented on the topic of *Asparaginase Therapy for Acute Lymphoblastic Leukemia, (ALL)*, brought to us from **EUSA Pharma USA, Inc.**



Following O'Hanlon Curry we heard from **Julie Eggen, LCSW**, from Nemours Children's Clinic at Sacred Heart Children's Hospital, Pensacola, Florida. Her lecture was on, *Staying Afloat on Stormy Seas: Dealing with Difficult People in Medical Settings*.



After a very delicious Italian buffet provided by FAPTP, the **Oncology Session** resumed with a presentation by **Craig MacArthur, MD**, entitled, *Neuroblastoma: The Good, the Bad, and the Ugly*.

Donna Eull, RN, BSN, MA, from Children's Hospitals and Clinics of Minnesota, Minneapolis, Minnesota, then presented on *Beyond Opioids – Managing Complex Pain Through an Interdisciplinary Approach*.



Next we heard from **Maura Fitzgerald, RN, MS, MA, CNS**, from Children's Hospitals and Clinics of Minnesota, Minneapolis, Minnesota. Ms. Fitzgerald spoke on *Complementary Alternative Therapies for Symptom Management*.



Wrapping up the seminar, was **Janie Walters**, our **Keynote Speaker**, with her presentation on, *This Little Engine Did... And So Can You!*



Following Maura Fitzgerald, we learned about the *Psychological Adaptation in Children with ALL while Receiving Maintenance Therapy given by Julie Fitzgerald, PhD, RN*, from William Paterson University, in Wayne, New Jersey. Ms. Fitzgerald presented on.

Ms. Walters helped to send all of the attendees home with a message of hope and inspiration, along with a smile on their faces.

Seminar Highlights

Each year we have a daily drawing for 3 gift baskets. This year the baskets were provided by All children's Hospital. Each basket contained luxurious "Spa" items, gift certificates, wine, cheese, sparkling cider, crackers, cookies, chocolates and Autumn/Fall themed knick-knacks to take home as a remembrance of their Seminar experience.. The following are the names and pictures of the three winners. Congratulations to all three winners!



Thursday, November 17th, the winner of the first basket was: **Lucky Hollingsworth, RN, CPON**, from Dell Children's Hospital in Austin, Texas.



Friday, November 18th, the winner of the 2nd basket was: **Diane Bowen, RN-C, AAS**, from Chris Evert Children's Hospital at Broward Health in Ft. Lauderdale, Florida



Last but not least, Saturday, November 19th, the winner of the 3rd basket was: **Carolyn Bell, RN, MS, CCRP, CPON**, from Children's Hospital of SW Florida at Lee Memorial Health System in Ft. Myers, Florida.

Seminar Highlights

FAPTP gratefully acknowledges the following organizations for their educational donations provided in support of the 2011 Seminar.

Platinum Level



Gold Level



EUSAPharma

octapharma

For the safe and optimal use of human proteins

Silver Level

All Children's Hospital
 Bayer Healthcare Pharmaceuticals
 Chris Evert Children's Hospital at Broward Health
 Joe DiMaggio Children's Hospital
 Matrix Health
 MedPro Rx

Bronze Level

The American Cancer Society, Florida Division
 Baxter Healthcare Corporation
 CSL Behring
 MedEx Biocare Pharmacy
 Novartis Hematology
 Sigma Tau Pharmaceuticals

News From the Centers



Our institution is thrilled to have memberships in both the Neuroblastoma and Medulloblastoma Translational Research Consortium (NMTRC) and our newest affiliation, the Pediatric Oncology Experimental Therapeutics Investigators' Consortium (POETIC). Through these early phase pediatric oncology research groups, we are able to complement the wide range of studies available through the Children's Oncology Group (COG). We offer many options for innovative therapy.

Examples of the many studies that are currently recruiting patients or will be within the next 6 months:

Sponsor	Phase	Summary	Principal Investigator
NMTRC	II	NMTRC003: A Phase II Preventative Trial of DFMO as a Single Agent in Patients with High Risk Neuroblastoma in Remission	Dr. Don Eslin (321) 841-8588
NMTRC	Pilot	NMTRC006: Molecular Guided Therapy for Refractory/ Recurrent Solid Tumors, Non-Hodgkins Lymphoma and Leukemia	Dr. Don Eslin (321) 841-8588
POETIC	II	POE08-01: Cetuximab given during Radiation Therapy followed by Maintenance Cetuximab and Irinotecan for Newly Diagnosed Diffuse Pontine and High-Grade Gliomas	Dr. Amy Smith (321) 841-8588
POETIC	Phase I/II	POE09-01: Vorinostat and Etoposide for Refractory Solid Tumors (<21 years at diagnosis)	Dr. Amy Smith (321) 841-8588

For more information on these groups please visit:

- POETIC website: www.poeticphase1.org
- NMTRC: <http://www.vai.org/Research/Labs/Neuroblastoma-Translational-Research/neuroblastoma-medulloblastoma.aspx>

We are excited to announce the opening of the Pediatric Brain Tumor Program, at Arnold Palmer Hospital for Children. Led by pediatric neuro-oncologist **Dr. Amy Smith**, this program treats children, adolescents, and young adults battling brain and spinal cord tumors while aggressively protecting their quality of life. The program includes dedicated nursing, social work, and research support specific to pediatric neuro-oncology.

Our team members bring together different perspectives to create a custom plan that covers the many needs families have during and after treatment. You can find out more about the team at: www.arnoldpalmerhospital.com/braintumorprogram

We would like to share the recent addition of **Lissette Murillo-Aristondo, ARNP** to our practice. Lissette will be focusing on care for the sickle cell and hemophilia patients seen at our institution. Lissette is a native Floridian, who obtained her undergraduate nursing degree and training from the University of Miami. After practicing in the Pediatric Cardiac Intensive Care Unit, at Miami Children's Hospital, she decided to pursue her Advance Practice degree at Florida International University, from where she obtained her Master's Degree. We are thrilled to have Lissette as part of our team!

For more information contact: **Emily Owens Pickle, CCRP**, Project Coordinator/CRA
(321)843-5498

News From the Centers



Nemours
Children's Clinic

The I Can Cope Support Group, in collaboration with American Cancer Society, is piloting the group in the pediatric setting at our center. The support group meets once a month and is open to parents of active patients, and parents of patients off therapy.

Monica Nebel has taken the position of KidsTRACK Program Manager, for Nemours Children's Hospital.
Aynalem Amare BSN, RN, joined the Hematology/Oncology clinic as Case Manager on February 27, 2012.
Jamie Wagner BSN, RN, joined the Hematology/Oncology clinic as Case Manager on March 26, 2012.

For more information, contact: **Kristen Gibbs, RN, BSN**, Clinical Research Nurse
 Nemours Children's Clinic-Orlando • 407-650-7652



Patient Outreach

R.O.C.K. Camp 2011 Hosted the Most Children Ever!

The American Cancer Society celebrated the 35th anniversary of R.O.C.K. Camp (Reaching Out to Cancer Kids) with partner Camp Boggy Creek during the summer of 2011. A total of 286 campers attended, which was the most children with cancer to attend camp since the program started in 1976.

We are gearing up for another fun and exciting summer with R.O.C.K. Camp in partnership with Camp Boggy Creek. The First Session took place on June 26-July 2nd for children from South Florida, including Miami, Ft. Lauderdale, West Palm Beach, Fort Myers and Tampa. The Second Session will take place on July 24-30th serving children from North Florida, including Pensacola, Panama City, Tallahassee, Gainesville, Jacksonville and Orlando. R.O.C.K. Camp is free to Florida children, ages 7-16, diagnosed with cancer and recommended by their physician.

R.O.C.K. Camp, in partnership with Camp Boggy, would not be possible without the generous volunteers and medical staff that give their time to be at camp. In 2011, FAPTP doctors volunteering their time and talent at camp included Brain Cauff, Kelly Sawczyn, Craig MacArthur, Bill Slayton, Eric Sandler and Cindy Gauger. They were assisted by the support of oncology nurses from around the state.



Dr. Kelly Sawczyn and a Camper



It's Cupcake Time



Game Time at the Pool



Happy 35th Anniversary
ROCK Camp

Patient Outreach (continued)



Great Shot



Hanging with my
New Friends



Golfzilla to the
Rescue

R.O.C.K. College Scholarship

The American Cancer Society will celebrate its 20th anniversary of the R.O.C.K. College Scholarship Program in 2012. Last year, 213 scholarships were awarded to young cancer survivors across the state of Florida.

Families R.O.C.K. Weekend

Families R.O.C.K. Weekend was held on October 28-30, 2011, in Orlando. This was the 11th anniversary of this event. The American Cancer Society welcomed 95 families who had a child newly diagnosed with cancer to this weekend retreat providing education and fun. Parents had the opportunity to learn more about the cancer disease from medical professionals in a casual setting while their children (patients and siblings) participated in scheduled activities.



Making New Friends at
Families ROCK Weekend



Team Support at
Families Rock Weekend



I'm a Survivor!



Special Friendships!

The next Families R.O.C.K. Weekend will be held on October 26-28, 2012, at the Universal Orlando Royal Pacific Resort. For more information about volunteer opportunities or attending the American Cancer Society's R.O.C.K. Families Weekend or other programs, please contact [Susan Lee](#), Director of Childhood Cancer at the American Cancer Society, 800-444-1410 ext. 4405.

SAVE THE DATE

November 15-17, 2012

For FAPTP's 35th annual seminar

Advances in Pediatric Hematology/Oncology

at the

Hyatt Regency Grand Cypress Orlando, Florida



- White sand beach by 21-acre Lake Windsong
- Around the corner from the Disney Village with scheduled shuttles to Disney/Sea World and various other theme parks and locations

- Private lake with miles of tropical nature trails for bicycling, horseback riding, and jogging
- 1/2-acre outdoor pool with 12 waterfalls, two water slides, 3 whirlpools, a sundeck, and game room



Advances in Pediatric Hematology/Oncology

November 15-17, 2012

Registration Form

3 Easy Ways to Register: Attendee Information

1 WEB
to <http://faptp.epi.usf.edu/>
(Print registration form and
mail with check)

2 FAX
(813) 910-5928
(Fax registration form
and mail check)

3 MAIL
FAPTP
3650 Spectrum Blvd, #100
Tampa, FL 33612

Full Name _____ Degree _____ First Name (for badge) _____

Employer Name (for badge) _____ Position/Title _____

Employer City/State (for badge) _____

License# / State (Required to obtain continuing education credit) _____

The following address is: Home Business

Address _____

City _____ State _____ Zip/Postal Code _____

Phone _____ E-mail _____



Please check here if you require special accommodations; we will contact you.

Conference Events

(The Registration Fee includes the following meals and social functions)

I plan to attend: (Check all that apply)

Thursday, November 15

Light Snack
11:15 - 11:45 am

Barbecue, DJ & Dancing-
Poolside
6:00 - 9 pm

Friday, November 16

Continental Breakfast
7:30 - 8:30 am

Sponsored Lunch
11:55 - 12:55 pm

Saturday, November 17

Continental Breakfast
7:30 - 8:30 am

Registration Fees

General Session Fees include program materials, Light snack, continental breakfasts, refreshment breaks and at least one luncheon and one dinner.

Early Seminar Registration

Postmarked on or before October 1, 2012
Healthcare Professionals.....\$250.00
Full-time Students*\$200.00
*Letter from faculty advisor must accompany registration.

Late Seminar Registration

Postmarked after October 1, 2012
Healthcare Professionals.....\$275.00
Full-time Students*\$225.00
*Letter from faculty advisor must accompany registration.

Single Day Rates are available. For more information on the single date rates, contact the Central Office at 813-396-9528.

Cancellation/Refund Policy: Written cancellation of registration received in the FAPTP Central Office on or before **October 15, 2012** will result in a refund minus a \$50 processing fee. After October 15th, no refund will be issued.

Registration Confirmation: You should receive confirmation of your registration by mail, fax or email. Registrations received after **November 2nd** will be processed on site.

Hotel Reservations

Please make room reservations directly with

Hyatt Regency Grand Cypress Hotel Direct Line: (407) 239-1234 • Toll Free: (800) 233-1234

Website: <http://grandcypress.hyatt.com>

Ask for the "Advances in Pediatric Hematology/Oncology - FAPTP" rate of \$139.00 for Single or Double Occupancy

Registration Payment

Payment must be made by check or money order with funds made available in U.S. Dollars made out to FAPTP and must accompany your registration form.

My registration fee of \$_____ is enclosed



Florida Association of Pediatric Tumor Programs, Inc.
3650 Spectrum Blvd., Suite 100
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813-396-9528
<http://www.faptop.org>

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