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## Incoming Newsletter

**Hi! I'm Lila Blum,** and I'm ready to make a change in the world, beginning with our small corner of Texas.

I am working for Project Joy and Hope this summer, and I am elated to be part of this organization that helps seriously ill children and their families.

I am most excited about the programs that PJ&H offers to suffering children and families. There is a huge need state-wide, and even nationally, that must be filled, and our organization is creating a shining example for other motivated people nationwide to emulate.

One of my goals during my time

working with Project Joy and Hope is to set a template for future newsletters. It is important to let everyone involved in our organization know what's going on. That way, we all stay enthusiastic about the changes PJ&H is working hard to create. I'd like to start off our newsletter



looking toward the future, that's why I dubbed it "Hopeful Happenings."

**Summer Intern Lila Blum has big ideas.**

The main sections of the newsletter will include spotlights on volunteers, families, board members, donors and progress with HOPE housing. Not every section can be included every time!

We'll also fit thank-you letters from families and highlight other agency programs. Of course, we will thank our generous donors and recognize grants and honors PJ&H is awarded.

I hope you are as enthused about the newsletter as I am! Look for new issues semi-annually. Here's to new beginnings!

—Lila Blum

## Spotlight on Scott Anderson: Board Member

**Scott Anderson** is a passionate, intelligent man in his mid-thirties. He joined Project Joy and Hope "in honor of Valerie Wheeler, because she was a great person." He's been involved in Project Joy and Hope since the very beginning, when it started as "an effort to support this area and help give money to the Houston Hospice Organization."



**Scott Anderson, along with Board Members and Staff, congratulates HOPE SCHOLAR, MARIA REYNA.**

"We never anticipated that PJ&H was going to be its own organization," but it definitely "fills holes that a lot of the organizations in the Houston Area do not fill," he said.

In Mr. Anderson's view, the purpose of PJ&H is not only to assist families made destitute by a child's illness, but also to instill faith in the family during the death process. "It's the antithesis of winning the lottery," said Scott with a sad chuckle. "Even some of the best insurances only cover part of the bill.

The parents feel obligated to leave their jobs to care for their child," making it difficult for families to avoid poverty. "An event like this [is] able to hurt a family member's view of the future, and they lose hope. So what I like seeing is that at PJ&H we had a play on words. We want to project joy, and we want to project hope. We give people hope and then they take it the next step further, to faith. "Faith is having not only the hope that something will happen but also the expectation that it will." Scott had family members die at early ages: his father and his brother. When he

**Story continued on page 4**

*"I can't keep up... there are just so many people to help."*

## Spotlight on Nell Turk: Volunteer

Nell Turk is a warm-hearted, compassionate woman working at the Southeast Texas Housing and Finance Corporation (SETH), where she is the office manager, doing "whatever needs to be done." Before 2001, Nell had worked for herself "on the profit-driven side". At SETH, we're giving away money.



Dedicated Volunteers  
Tammy Arrington & Nell Turk

You wouldn't think that's hard to do, but sometimes [it is]. We have to have income, but it's not the bottom line that matters most. It's a different atmosphere because the goal is helping the most

people," Nell glowed. She clearly enjoys her work and finds value in assisting lower income families in a sensible way, securing single-family

residences.

Nell became involved with Project Joy and Hope through SETH. "In 2001, SETH owned a number of multi-family properties, and they donated one to PJ&H for their first Hope House." Mrs. Turk was quite inspired when she met Jan Wheeler, EdD, Executive Director of PJ&H; they had a good rapport from the beginning. "Jan is a whirlwind," Nell murmured, "She's really something else. I wonder when she sleeps; I think she must sleep with one foot on the floor, ready to go." Besides her admiration, she considers Dr. Wheeler "to be a friend. I think she's one of the most wonderful women I've ever met. She's very driven; I don't know how she does what she does."

The pair seemed to have been destined to work together. Nell's late husband died in

1998, and she "was attending grief support at [Jan's] church, and the other ladies in the grief support group were talking about Valerie, and how ill she was." Nell didn't know much about Valerie's story or about Jan until she began working at SETH, which had already begun working with PJ&H and the Hope Housing Project. Nell speaks with wonder, "What a small, small world." Together, Jan and Nell worked hard and "watched Hope Housing grow."

Nell enjoys working with Project Joy and Hope immensely. "I liked the fact that it was young and growing and I could watch it grow. I like the challenge." Currently, she is the publicity chairperson for the annual gala and golf tournament; in the past she also served as co-chair of the silent auction and volunteered at the

[Story continued on page 4](#)

## Texas Pediatric Palliative Care Consortium

The Texas Pediatric Palliative Care Consortium (TPPCC), founded in 2007, is a statewide coalition of interdisciplinary pediatric palliative care providers, advocates, and parent representatives. Its mission is to optimize the quality of life for children living with life-threatening conditions (CLWLTC) and their families in Texas, without regard to care setting, family demographics, or financial status. TPPCC works toward its overall goal using a multi-pronged CARE strategy—Clinical Care, Advocacy, Research, and Education, each prong being a crucial building block for success.

Stacy Smith, RN, BSN, heads the Clinical Care work group. Creating and sharing resources and information for the development and delivery of pediatric palliative care services enhances the pediatric palliative care capacity and effectiveness of health care providers.

Melody Hellsten, RN, BSN, MA, PNP, is in charge of the Advocacy work group, enhancing the awareness of health care administrators, state agencies and legislators regarding the need for optimal family-centered pediatric palliative

care in Texas. Beginning in 2009, the TPPCC will team up with Bob Fine, MD and Tom Mayo, JD and other members of the Texas End-of-Life Coalition to explain the necessity of advance care planning and individual choice at the end of life



[Story continued on page 5](#)



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# Pedi-HOPE Conference 2009

The Texas Pediatric Palliative Care Consortium (TPPCC) held its first annual Pedi-HOPE (HOspice and Palliative Care Essentials) Conference in Austin on June 20<sup>th</sup>, 2009.

With the support of the Texas Pediatric Society Foundation, Texas New Mexico Hospice Organization, and the Texas Association of Palliative Medicine,

TPPCC attracted 52 healthcare providers from across Texas interested in furthering their knowledge of pediatric palliative medicine, especially concerning communication, decision-making, managing grief and loss, pain and



Active learners at the 2009 Pedi-HOPE Conference

symptom management, barriers encountered in palliative care, and meeting the spiritual need of patients, families and caregivers. Policy makers from the Texas Department of Aging and Disability Services (DADS) were invited to the conference in hopes that this intensive course on pediatric palliative medicine would give them new perspective as they administer benefits to patients and families and work with policymakers. The conference was very well-received, and the attendees offered much positive feedback.

Attendees were highly experienced, with an average of 19 years of healthcare experience represented several healthcare disciplines. Giving up their Saturday, 52 attendees listened and actively participated in lectures by the conference's faculty on topics addressing a broad spectrum of issues surrounding pediatric palliative care.

The goal of the 2009 Pedi-HOPE conference was to educate care providers to be better prepared, confident and equipped to provide the best quality of life possible for children living with life-threatening conditions (CLWLTC) and their families as well as to eliminate systematic misgivings and errors consistently made in pediatric palliative care. Healthcare policy was addressed, enabling benefits administrators and program leaders to better understand benefits available to

facilitate the delivery of pediatric palliative care.

Nurse practitioner Melody Hellsten discussed the demographics of CLWLTC and addressed their frequently unmet needs. One participant observed that Ms. Hellsten's presentation encouraged providers "to bring the

palliative care team in earlier" and to discuss palliative care at the first family meeting. More positive feedback from attendees included a newfound confidence in knowing she was providing care that is beneficial, while another gained new

"awareness of what families need when caring for a child with a terminal illness" and intends to integrate a 'life plan' into her care of CLWLTC.

Dr. Marcia Levetown's presentation focused on creating a trusting relationship with CLWLTC and their families using better communication, and the importance of interdisciplinary collaboration in assisting the patient and family. Attendees were inspired by Dr. Levetown's "passionate" delivery and message. They learned to "treat parents as experts and partners in the care of the child" while being reminded of "the importance of seeing a person, not a dying child."

Dr. Barbara Jones' presentation identified the needs of and losses experienced by CLWLTC and their families, noting ways to encourage their communities to help them cope with significant loss. Some participants commented that her lecture clarified "suffering vs. pain" and presented "how to approach a child and what language to use" and to help direct care.

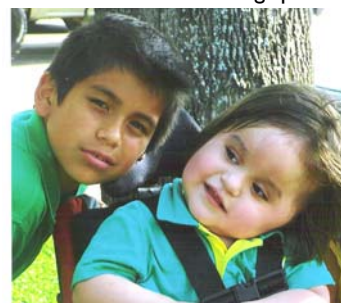
Dr. Sarah Legett and Kendra Koch organized a parent roundtable featuring Diana Kuai, Sanjay Radhakrishnan, and Chris Hubner, to discuss parent perspectives on parenting a CLWLTC, navigating the medical system, as well as personal perspectives on grief, loss, and bereavement. The group also focused on the need for timely symptom management as well as the importance of clear and open communication between the healthcare providers and the parents. Learners reported having a better sense of what parents need and want during the palliative care process, especially "frequent, timely communication" and for the team to be "clear [and] honest."

Dr. Bob Bash focused on identifying the types of pain commonly experienced by CLWLTC and the determination of appropriate therapies, meanwhile discussing techniques to optimize communication and the physical examination of CLWLTC. Attendees came away with a better appreciation of the diagnostic and therapeutic value of active listening, many now recognizing the need to wait until a parent or child finishes speaking before formulating a response. They also recognized that the usual adult "steps of pain control [are] not likely appropriate for youth."

Dr. Sarah Legett, Dr. Todd Pearson, and Stacy Smith, RN served as faculty for the spirituality session. Their presentation considered the influence of spirituality on medical decision-making, the distinction between spirituality and religion, and tools for assessing spiritual needs in palliative care. Attendees acknowledged the need to assign higher priority to "acknowledging the spirituality of different cultures" and discussing spirituality with CLWLTC and their families.

They understood from the discussion that the spiritual belief and needs of "children can't be assessed with a questionnaire" and that it is important as a provider to "ask about spirituality [one does not] understand"

while being careful "not to offend anyone's beliefs."



Anthony and Fernando, Hope Housing Residents

Story continued on page 4

## Volunteer (continued)

Mothers' Retreat. "It's really overpowering to see these mothers when they come in, and the pain and the misery that they're in." By the end of the retreat, all of the women who had been "strangers to each other" are now "best friends, and they have the tools to mend their hearts a little bit." Nell shakes her head like she can't believe it. "It's really fabulous," she says, "it really is. And these ladies go on, and their pain is not gone, but they have a better idea of how to deal with it and what to focus on besides their loss. That's one of my favorite parts of being involved with PJ&H."



Volunteer Nell Turk greets Joy & Hope gala guests.

"Fundraising is a lot of what we do," said Nell, "PJ&H always needs more money. There are so many families we don't reach. There are so many sick children, and the number of parents that have lost a child is just astronomical." There are always more families to reach and more families willing to give. In order to find those families willing to give in this economy, Nell says, "we just have to be more creative. ..This is operating money that we need so desperately."

An 8-year veteran at PJ&H, what Nell values most is "interaction with the families. Here at the [SETH] office, we sponsor a holiday gift program; we select one of the families in the Hope Houses and between the staff here and our board of directors, we make donations and fulfill their Holiday wishes. The very first family we adopted was [...] so gracious. They sat there and made us coffee, and they had to open every package while we were there. The look on their faces sold me from then on because they were so appreciative of everything that's ever been done for them. That was in 2001, and to my knowledge, the father still calls Jan on Christmas Day every year."

When asked what she would change about the world, if she could Nell's heartfelt answer is surprising. It seems probable that she would focus on the tragic death of her husband and the missed diagnosis of lung cancer. But Nell is a strong woman who is able to

absorb pain and keep moving, even though "there's always a part of you that doesn't get past that." After a moment of thought, she replied with conviction, "I wish the world were more compassionate. There are some people in the world that are very compassionate, but as a whole, the world is really very cruel. I have been crushed by the insensitivity I have experienced in others, but I have discovered since then that it is quite common. Our society thinks, 'out of sight, out of mind.'"

Overall, says Nell, her experience with Project Joy and Hope "has been really amazing. In the

beginning, I knew most of the families. Now, there've been so many that I can't keep up with them. There are just so many people to help."

## Pedi-HOPE (continued)

The last session encompassed problems encountered in the care of CLWLTC and strategies for improving their care; it was presented as a Q&A by the entire faculty. Participants "realized that [they] don't have to be perfect [...] if [they] listen with dignity and respect." Many took home an important message about hope—"hope is whatever we make it." Overall, the healthcare professionals attending the inaugural Pediatric HOPE conference affirmed that they were better providers for having attended the conference. The faculty, sponsors and organizers of the Pedi-HOPE conference were pleased by the turnout from the "LISTEN WITH DIGNITY AND RESPECT." Texas health-care community, and they were delighted by the attendance of healthcare policy makers from the Texas Department of Aging and Disability Services, who commented that the conference had substantially increased their knowledge of pediatric palliative care and the effects upon relevant healthcare policy.

In all, the 2009 Pedi-HOPE conference was a great success, accomplishing the goals of educating the community in pediatric palliative care and enabling Texas healthcare providers to feel more comfortable and well -equipped to care for CLWLTC and their families. Planning for a two-day Pedi-HOPE in 2010 is now underway.

## Board Member (continued)

sees the families that PJ&H helps, he "know[s] what they've done, what they've walked through," and so feels a sense of understanding toward the families.

Scott likes about PJ&H "that it normalizes death." He promotes the idea that "birth and death are a part of life. They are the balance and equivalency," and that, as a society, we need to come to terms with death in a healthy way. By discussing death and illness, and by letting families know they are not alone, PJ&H normalizes death, making it a more bearable experience.

According to Scott, the role of a board member is to **"I want to make sure that 'is bring help, [to] PJ&H will not disappear."** bring

additional resources, and [to] be supportive." He has volunteered in several ways with PJ&H, "from flipping hot dogs and hamburgers [...] to updating the website." He "always has on the hat of looking out for the best interests of the organization." One of the board's major jobs is "directing the organization's strategic moves, including fundraising or starting new programs and allocating money ." It also determines how much money to give in scholarships and how many students will receive them.

Scott enjoys most about working with PJ&H "the opportunity to give out scholarships. Seeing the kids we've affected positively [and] how we helped give them hope; that's the best part." His priorities have shifted as a result of working with families in such dire straits. "Hearing about the adversity these people have overcome and seeing them face-to-face, it really minimizes other concerns. All worries are put into perspective."

The only thing Scott would change about PJ&H is its long-term stability. He wishes to have security in the knowledge that, decades from now, "the organization will be a stand-alone organization that has no end in sight; that it has eternal life, that it's financially secure, that it has developed programs, and will not disappear."

[www.joyandhope.org](http://www.joyandhope.org)

# TPPCC (continued)

to the Texas legislature, defending Texas' innovative and precedent-setting legislative initiatives enacted in the Texas Advance Directive Act of 2003.

The Advocacy work group is also creating strategies to capitalize on the Frew lawsuit monies (US Supreme Court, 2004) to improve pediatric palliative care in Texas. The goal is to use existing networks and telephonic services to provide backup to agencies that already provide pediatric palliative care, whether at home, in the hospital or elsewhere. With easy access to an expert and the additional possibility of onsite training, the quality of care these agencies provide to CLWLTC and their families can be dramatically improved. The effort would also include creating a statewide guide for management of symptoms to use as a readily accessible resource for direct care providers.

TPPCC's advocacy efforts also include active support for Senate Bill 1150, the Advance Planning and Compassionate Care Act of 2009, which uses a variety of strategies to improve end of life care, including increased education and support for advance care planning, education of healthcare professionals in palliative and end of life care for patients of all ages, and increased research dollars to broaden the evidence base related to palliative care. The Bill directs the Secretary of Health and Human Services, through several federal agencies, to develop a national campaign to inform the public of the importance of advance care planning and of an individual's right to direct and participate in health care decisions. For more infor-

mation on the Bill, visit <http://www.govtrack.us/congress/bill.xpd?bill=s111-1150>.

Closer to home, TPPCC has created a relationship with the Texas Department of Aging and Disability Services (DADS). Jan Wheeler, EdD, has been invited to participate in DADS' quarterly meetings, representing TPPCC.



TPPCC Chairperson Melody Hellsten presents "The Patient Universe" to Pedi-HOPE attendees. An Audience Response System allowed learners to provide immediate feedback and stimulated discussion.

By increasing the evidence base for family-centered pediatric palliative care through collaborative research, Dr. Bob Bash and his team of volunteers in the Research work group hope to optimize PPC in Texas. Planned research effort will result in a better understanding of current availability of PPC in Texas, candidates for PPC who have easy access to PPC and those who do not, current PPC volumes of service, who provides it—university-based programs, home health agencies, hospices, nursing homes, and where it is available, whether only in urban areas or throughout the state. The research work group will use this information to discern effective models of delivering PPC in Texas as well as means to increase its availability, whether by further training providers, propagating successful

business plans, or increasing access to information.

Dr. Marcia Levetown heads up the Education work group, furthering the PPC knowledge of families and health care providers in the state of Texas. "Our first major effort was the 2009 Pedi-

-HOPE Conference," she said, "and for a first outing, we felt we had great success. We were provided invaluable support by the Texas New Mexico Hospice Organization and the personal efforts of Larry Farrow and Brandi Baker, as well as the Texas Academy of Palliative Medicine and the dedication of Dr. Ron and Mrs. Carla Crossno, as well as seed money from the Texas Pediatric Society Foundation, and financial and practical support from John McLeod, of Palliative Drug Care Prescription Management. We were buoyed by the wonderful evaluations, in large measure due

to the presence of parents as mentors, wonderful professional faculty and interactive methods of teaching. We are excited that many participants asked for a two-day conference." Next year's conference will be held July 9<sup>th</sup> and 10<sup>th</sup> in Austin at the Texas Hospital Association building, courtesy of Larry Farrow and the TNMHO. "We're excited to be able to count on TNMHO and TAPM for their continued support," she said.

The TPPCC needs as many volunteers as possible to reach its goals for ongoing improvements in pediatric palliative care. If you would like to join the Texas Pediatric Palliative Care Consortium, helping to achieve these goals, please complete the form at <http://joyandhope.org/aboutus/ppc.php> BE PART OF THE SOLUTION!

## YOU CAN MAKE A DIFFERENCE!

To donate to **Project Joy and Hope**, please fax this completed form to 713-944-5533 or mail to Project Joy and Hope, PO Box 5111, Pasadena, TX 77508



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Founded in 2000, **Project Joy and Hope** strives to support families through the difficult and unpredictable journey of a child's life-threatening condition by providing hands-on personal, practical and psychological support. Community involvement and volunteerism are central to all programs.

PJ&H serves as an advisor to and role model for similar programs throughout Texas and the United States, and advances its mission through community awareness, education, programs, and resource development.

"Your organization has truly lived up to its name, in the **JOY AND HOPE** that it has given to our whole family."

Karen Lee, 2009 Hope House Resident

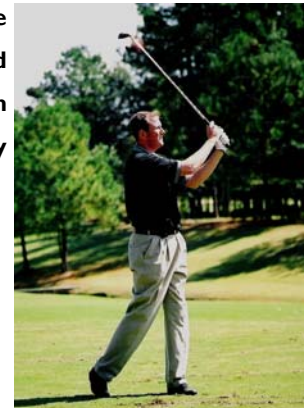
To learn more or volunteer, visit the PJ&H website at: <http://joyandhope.org>.

Agency programs:

- HOPE Housing
- Family Grants
- Parent Support Line
- Tapestry Retreats
- HOPE Scholarships
- Holiday Gift Project
- Texas Pediatric Palliative Care Consortium ( TPPCC )

## Support the Annual Golf Classic and Gala!

The Board of Directors of Project Joy and Hope invites you to our 2009 Annual Golf Classic and Gala. Your sponsorship and participation provides ongoing support for our agency programs.



**Annual Golf Classic: Columbus Day Monday  
October 12 Noon shotgun start  
Cypresswood Golf Course - Spring, Texas  
Proud Host: Northville Product Services  
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