

**Family Involvement  
Pediatric Pulmonary Centers  
2006**

**Pediatric Pulmonary Centers  
Family Involvement**

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**Survey Results of Family Involvement Across Pediatric Pulmonary Centers\* -- March, 2006**

Type of Involvement	Past Grant: % of Centers Reporting Family Involvement	% of Centers Planned (Projected) Increase in Family Involvement	Projected Total % (1-2 year plan?)
<b>Advisory Board</b>	66 %	34 %	100 %
<b>Didactic / Core</b>	83 %	No answer?	83 %
<b>Environment</b>	100 %	No change	100 %
<b>Capstone/ Leadership Project</b>	16 %	50%	66%
<b>Teachers/ Mentor</b>	50 %	50%	100%
<b>Consultant</b>	66 %	34 %	100%
<b>Faculty</b>	0 %	66 %	66 %

**PPC Self-Identified Strongest Area of Family Involvement\***

Center	Family Advisory Board	Family Resource Partner	Family Support Group	Families as Faculty/Core Curriculum	Research
<b>Arizona</b>	<b>X</b>		<b>X</b>	<b>X</b>	
<b>Florida</b>	<b>X</b>	<b>X</b>			
<b>Washington</b>					<b>X</b>
<b>Wisconsin</b>					
<b>UAB</b>				<b>X</b>	

\*As evidenced by the Survey Results and individual PPC Family Involvement Tables, all PPCs appear to have, or to be planning for, family involvement efforts in each of the major areas (e.g., Family Advisory Boards, Family as Faculty, etc). The Family Involvement Narratives identify and expand upon the area(s) in which PPC faculty feel that their PPC has the greatest experience and strength.

**PPC FAMILY INVOLVEMENT IN TRAINING-CURRENT PROGRESS  
CENTER: ARIZONA**

Date: 2006

<b>WHO</b> How recruited Length of time Objective	<b>WHAT-Activities</b>	<b>OUTCOME MEASURES/ EVALUATION</b>	<b>RESOURCES</b>	<b>COMMENTS</b>
<b>Individual Board Members</b>	<ul style="list-style-type: none"> <li>Evaluates Curriculum</li> <li>Attends Advisory Board Meetings</li> </ul>	<ul style="list-style-type: none"> <li>Feedback to PPC</li> <li>Generates new ideas</li> </ul>		
<b>Co-Instructors</b>	<ul style="list-style-type: none"> <li>Family members present along with Faculty members to trainees.</li> </ul>	<ul style="list-style-type: none"> <li>Evaluation from trainees</li> </ul>		
<b>Co-facilitator of Support Group</b>	<ul style="list-style-type: none"> <li>Family member co-facilitates support groups along with faculty member and trainee.</li> </ul>	<ul style="list-style-type: none"> <li>Evaluation from support group attendees.</li> </ul>		
<b>Family Support Liaison</b>	<ul style="list-style-type: none"> <li>Parent identified as a liaison for newly diagnosed patients and family members.</li> </ul>	<ul style="list-style-type: none"> <li>Feedback from Patients and Family members.</li> </ul>		
<b>CURRENT PLANNING/ RECRUITMENT</b>				
<b>Family Resource Partner</b>	<ul style="list-style-type: none"> <li>Fill Paid position to coordinate a Family Advisory Board</li> <li>Assist in developing a pool of family members</li> </ul>	<ul style="list-style-type: none"> <li>Feedback</li> <li>Pool of family members</li> </ul>		

	to speak at presentations. <ul style="list-style-type: none"> <li>• Assist in developing a Family Support Plan for various pulmonary issues.</li> </ul>			
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**Arizona**

1. *What do you view as your strongest area(s) of family involvement*

Consistent family presence on the Advisory Board and at family support group meetings.  
 Improved visibility and involvement in Core Curriculum.  
 Support Group Involvement

Most importantly, I think as a PPC, we are very mindful about asking "how can we involve the family in what we do?" -- Clinically, community, education, advocacy, etc. It shows in the kind of projects we do; community presentations and outreach efforts.

2. *For each area, (discussing only one area is fine, but please identify and discuss at least one) please give a brief descriptive narrative about how you developed this aspect of family involvement. Please include:*

a. *Chronological narrative (what happened, in what general order)*

Advisory Board: We first formalized three parent positions on the Advisory Board and had great enthusiasm, participation, input, and feedback. It is to the point, now, however, that we need one parent who can coordinate parents to develop a Parents Advisory Board. Someone who can stay relatively connected and interested in ways to have input/serve.

Family support group: This activity was initiated 4 yrs ago by our social worker. This has evolved over the years into a great forum for education, support, and interaction between parents and the healthcare team. It is held once a month with the Social Worker and her trainee. As parents bring up concerns, they become topics for their meetings.

Core Curriculum: Parents began lecturing with the nutrition lecture. This year, the parents will have their own lecture slot in the core curriculum series.

Multi-media projects: Parents have been part of the trainee's multi-media projects. For example: one of the Social Worker trainee interviewed a family and incorporated the parents, siblings and patients point of view and opinion. There were also brochures developed titled "The Effects of Chronic Illness on Psychosocial Development" with much input from families.

Collaborations/Advocacy: The ultimate family centered care/involvement is to change policy. We are credited with doing that with the Tucson Parks and Recreation where obesity/nutrition is concerned. We are assisting them in standardizing their nutrition curriculum (CATCH) in ALL of their centers to improve the obesity prevalence in Tucson.

- 1) Formalizing the Paid Parent's position.

*b. Barriers that got in the way*

Technical formalities and life. One set of parents named in the grant was not able to continue due to family and work obligations. We had to go through a formal change process to open the position to other parents.

*c. If barriers were overcome, how did this happen?*

Creating the paid parent's job description and opened it up for people to apply through the University process.

*3. What advice would you give other training programs who are trying to develop their family involvement in this area?*

Family involvement can be at all levels and in all areas of our work with children and youth with special health care needs -- keep an open mind!

*4. How is your family involvement funded (or, is it not funded)?* Through the PPC Grant only

**PPC FAMILY INVOLVEMENT IN TRAINING-CURRENT PROGRESS  
CENTER: FLORIDA**

Date: 2006

<b>WHO</b> How recruited Length of time Objective	<b>WHAT-Activities</b>	<b>OUTCOME MEASURES/ EVALUATION</b>	<b>RESOURCES</b>	<b>COMMENTS</b>
<b>Family Resource Partner</b>	<ul style="list-style-type: none"> <li>• Organized Family Advisory Board (FAB)</li> <li>• Networking</li> <li>• Pizza program</li> </ul>	<ul style="list-style-type: none"> <li>• Family Resource Partner feedback to PPC</li> </ul>	Paid for 5 hours /week, but works more hours without pay.	
<b>Family Advisory Board</b>	<ul style="list-style-type: none"> <li>• Designed Family Satisfaction Survey</li> <li>• Designing Family Involvement Survey</li> </ul>	<ul style="list-style-type: none"> <li>• Family involvement survey</li> </ul>		
<b>Individual Board Member</b>	<ul style="list-style-type: none"> <li>• Co-teaching "Psychosocial Issues in CF" with Susan Horkey</li> <li>• Developing "Families as Faculty Program"</li> <li>• Representing families on hospital wide committee related to building move</li> </ul>	<ul style="list-style-type: none"> <li>• Successful development of Families as Faculty program</li> <li>• Feedback from trainees</li> </ul>		
<b>Florida Institute for Family Involvement</b>	<ul style="list-style-type: none"> <li>• Assisted in hiring and job description of Family Resource Partner</li> <li>• Provide guidance to Family Resource Partner</li> </ul>		Paid	

<b>ONGOING PLANNING/ RECRUITMENT</b>	<ul style="list-style-type: none"> <li>• Develop Family-As-Faculty Program</li> <li>• Expand FAB</li> <li>• Increase FAB involvement in division and department policy-making</li> </ul>			
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**University of Florida**

1. *What do you view as your strongest area(s) of family involvement*

The UF PPC has hired a Family Resource Partner (FRP) and she has developed a Family Advisory Board (FAB). This board has advised us on training activities, participated in training, developed family-to-family support activities and advised the PPC on family issues related to the upcoming move of the inpatient pediatric unit to a free standing hospital.

a. *Chronological narrative (what happened, in what general order)*

The UF PPC had tried for a number of years to increase our “Family Involvement.” We had put fliers in the PFT lab, called families who might be interested and asked clinic staff to identify likely candidates. We tried inviting a few family members to our annual PPC Advisory Board meeting and we also tried inviting family members to our PPC faculty meetings, on a quarterly basis. Both of these efforts met with a small initial success, but then dwindled.

We then consulted with The Florida Institute for Family Involvement (FIFI) a family advocacy agency located about an hour away. The FIFI director came to one of our PPC meetings, listened to our interests and concerns and then drafted a tentative plan for developing family involvement. She recommended hiring a FRP as a first step and then having this individual help us with future aspects of family involvement (e.g., Family Advisory Board, family involvement in training, etc).

The FIFI plan included developing a focus group of families who could advise us on what a job description for a FRP should include. FIFI provided us with fliers for soliciting focus group participants and advised us on how to recruit. A FIFI staff member ran the focus group and two PPC faculty members attended as “silent participants.” The focus group questions and answers addressed both participants’ views of the PPCs needs for family input and the specific role a FRP would play.

FIFI then drafted a job description, which PPC faculty reviewed and revised. When a mutually satisfactory job description had been developed, it was posted in the clinic and sent to CF families. Three parents initially applied, but one did not follow through. FIFI conducted initial interviews with the remaining two parents and then the PPC faculty interviewed the candidates. As it turned out, one of the parents was foreign born and did not have a work visa. We hired the remaining parent. The foreign born mother has been an active participant on the FAB, in a volunteer capacity.



The program started with the hiring of a part time Family Resource Partner, the mother of a teenager with cystic fibrosis. The Family Resource Partner has recruited families and established a Family Advisory Board (FAB). This Board meets monthly and, in collaboration with the PPC, develops projects that will help families and assist PPC faculty with our clinical and educational responsibilities. Current projects in place or under development are: 1) Family-to-Family support for in and out patients; 2) Co-teaching between parents and faculty; 3) the development of a "Families as Faculty" program; 3) the development of a PPC family website; 4) Family input into the AGH move and family resources at AGH; 5) Family input into a patient satisfaction survey. The FAB also consults with PPC faculty in planning educational offerings (e.g., the annual "Updates" conference; CF Family Education Day).

*b. Barriers that got in the way*

One potential barrier involved mixed views among PPC faculty of the desired capabilities and competencies of the FRP. While on paper we agreed about what we were looking for, our two candidates had two very different sets of strengths. One candidate was a warm, down-to-earth mother whose only previous employment had been as a waitress. She touched our hearts when, during the interview, she said, "I've been training all my life for this job." The other was an equally warm but more highly educated, with more advanced organizational and administrative skills. The first was drawn to the parent-helping-parent aspect of the job, the second to the development of a Family Advisory Board that might have broader impact.

Lack of clarity about the role of FIFI turns out to have been a barrier, although this may have resulted from communication challenges. After several months, FIFI felt that they were not playing a particularly useful role in supervising the FRP and withdrew their services. In large part this was due to the fact that FIFI was undergoing both administrative and funding changes and could only follow through with their highest priority commitments. However, it also appears that they may have felt that the FRP should have followed FIFI's ideas about her role and activities, rather than the PPCs. The challenges involved in the relationship between FIFI and the PPC are still not clear.

Another barrier has been, and continues to be, limited funding. At present, we are only able to pay our FRP for five hours/week. We do not have funding for paying families to help teach or to expand our program.

A final barrier involves level of impact that the division and organization will accept from an FRP. For example, it was difficult (impossible) to obtain access for a family member to the core committee that was in charge of the move to the free standing Children's Hospital. The degree to which the division would accept the input of a family member has not yet been tested, but might be limited (in other words, would the faculty allow/encourage family participation in all sessions of the Fellows' Core Curriculum, or in patient care meetings?).

*c. If barriers were overcome, how did this happen?*

In terms of the first barrier, we were simply very lucky. The second (more administratively-oriented) candidate has volunteered her time. Her skills and those of the FRP complement each other extremely well and the two women also appear to get along well. Each shows immense initiative in her own area of interest, but the two do not conflict.

In terms of funding and in terms of determining the extent to which the organization will tolerate family involvement, these both remain barriers.

*d. If barriers have not been overcome, how does this impact the family involvement?*

Fortunately, most of the potential barriers have been overcome. The FRP and the runner-up candidate work well together and the latter has been generous in volunteering her time. The withdrawal of FIFI's services has not had any short term consequences, although the long term consequences not having their consultation remains to be seen.

The financial barriers remain the most significant ones. Without additional funding we will have difficulty expanding our family involvement, in terms of the people we can hire, the programs we can develop and the actual influence family members can have.

*e. Did you utilize specific resources? If so, what were they? Would you recommend these to others?*

The use of FIFI's consultation was immensely helpful in terms of the guidance they provided and the confidence they gave us. When such consultation is available, we would recommend it, although guidance from other training programs may, in the long run, be equally effective.

*f. What else, if anything, was particularly helpful as you were developing this aspect of family involvement?*

FIFI's guidance and the fact that we had some funding to hire an FRP.

*g. What advice would you give other training programs who are trying to develop their family involvement in this area?*

Developing family involvement takes time, patience and, above all money. It is helpful to have an FRP who has the time and credibility (with families) to develop further aspects of family involvement (FAB, family-to-family support, involvement in training).

*h. How is your family involvement funded (or, is it not funded)?*

We are funded through the PPC grant, with a small amount of additional funding from the Department of Pediatrics.

**PPC FAMILY INVOLVEMENT IN TRAINING-CURRENT PROGRESS  
CENTER: WASHINGTON**

Date: 2006

<b>WHO</b> How recruited Length of time Objective	<b>WHAT-Activities</b>	<b>OUTCOME MEASURES/ EVALUATION</b>	<b>RESOURCES</b>	<b>COMMENTS</b>
<b>Family Advisory Committee</b> <b>Recruited:</b> from known families by Greg Redding. <b>Started:</b> 9 months ago <b>Objective(s):</b> Provide family input into training program.	<ul style="list-style-type: none"> <li>• Orientation</li> <li>• Assisted with planning of National Conference</li> <li>• To review Core Seminars</li> <li>• To participate in seminars and training</li> </ul>			
<b>Recruited Parent Co-Investigator for NIH grant</b> <b>Recruited by:</b> Gail Kieckhefer, ARNP, PhD <b>Started:</b> 4 yrs ago <b>Objective:</b> Insure family voice in design, randomized clinical trial of, and refinement of a parent support and education program for parents of children with special health needs	Advises PI on decisions re grant Co-facilitates many classes Is support person to other parent and professional co-facilitators Participating in the competing renewal application	Grant was funded by AHRQ with comments that having a parent co-investigator was a positive  Classes held successfully  Has made significant impact on grant decisions  Article on here role ready for submission  Competing will go in 11/06	Initially time and effort to look for and train  Added effort throughout the grant for her AND for the entire team to be open to changing roles of everyone when parent is fully at the table in grant work	Writing the article helped us to see what challenges we had faced (from her and others perspectives) and to offer advice to others embarking on this role.  I would do it again with the right person, for the right grant, at the right fte.
<b>Recruited 2 Parents to help revise a parents support and education curriculum for parents' s</b>	Review curriculum  Advise changes, confirm directions		\$ on our part  Consistent time on their part given their other family & work needs	Wish we could have found more ethnically/economically more diverse parents. Used the Children's

<p><b>of children with special health needs</b>  <b>Recruited by :</b> Gail Kieckhefer, ARNP, PhD  <b>For:</b> 1 year  <b>Objective:</b> Insure best relevance  Lesson the burden on the parent –co-investigator as the only parent voice</p>				<p>groups as it was IRB easy and also knew they would be open and up-front if disagreed and didn't have time to nurture people to get to that point. In the future could use the co-facilitators in this role to bring diversity and they ARE usefully critical</p>
<p><b>Recruited 3 parents of CSHN to co facilitate research education classes with health care professional</b>  <b>Recruited by:</b> Gail Kieckhefer, ARNP, PhD.  For: 2 years</p>	<p>Teach classes</p> <p>Provide evaluative feed back on class to guide revisions</p> <p>Respond to research team on proposed revisions</p>	<p>\$ on our part</p> <p>Consistent time on their part given their family needs</p> <p>At time feed back differs from one an other and that of the other team members theoretical beliefs so requires more openness on the part of all and the ability for the entire team to live with greater diversity of thought and increase sense of ambiguity</p>	<p>Classes run according to manual</p> <p>Insightful feedback complementary with the evaluation of parent participants and professional Co-facilitators</p>	<p>Good racial and child condition diversity</p> <p>Still want more diversity of thought</p>
<p><b>CURRENT PLANNING/ RECRUITMENT</b></p> <ul style="list-style-type: none"> <li>• Increase members for FAC.</li> <li>• Recruit for diversity of members.</li> <li>• Consider FAC coordinator (paid family)</li> <li>• Provide funding for participation.</li> </ul>				

## Washington

### 1. *Strongest area of family involvement: Research Projects-Gail Kieckhefer, ARNP*

Parents in all aspects of a AHRQ research project and parent as a co-investigator

#### a. *Chronological Narrative*

Decision made that parents needed to be full partners in research

Solicited a parent in grant generation

Listed parent as co-investigator

Had parent focus groups/ consultants after grant was funded to work out implementation details.

We now have 3 parents of children with special health care needs involved

Submitted proposal for 4 more years funding with parent continuing as co-investigator. Parents are involved in all phases of the research from inception to dissemination

#### b. *Barriers*

Misunderstanding of roles

New roles to sort out

Funding at equitable levels

Not having just one parent feeling isolated

### 2. *Overcoming Barriers*

Open communication

Continued work on barriers as process goes on

3. *Specific Resources*

Lyn Kratz, Senior Consultant, Family Services, is on the grant and is consistent source of experience and wisdom.

4. *What else was helpful in developing this aspect of family involvement?*

A sustained belief that parents ARE true partners

Insightful, capable parents who become involved

5. *Advice*

Try it but go slow

We have submitted an article on this process recently

6. *Funding*

Through PPC grant

**PPC FAMILY INVOLVEMENT IN TRAINING-CURRENT PROGRESS  
CENTER: WISCONSIN**

**DATE: 2006**

<b>WHO How recruited Length of time Objective</b>	<b>WHAT-Activities</b>	<b>OUTCOME MEASURES/ EVALUATION</b>	<b>RESOURCES</b>	<b>COMMENTS</b>
Approached Family	One Year Later	Used monthly with medical students in a one hour Friday seminar. Also used in the PPC course/student evaluations	PPC	
Approached Family	"Bridging the Gap: One Family's Journey from Diagnosis to Adaptation. Parents also participate 1 week online during the course	Used in the PPC course and when families want to hear about other families that has children with a trach. Also CE option throughout the state. Student course evaluations	PPC pays family \$200.00	
Approached Several Families	Trach Manual	Used with all families who have a child with a trach. Ask family feedback on how training is going.	PPC	
Approached your adults to review	Moving ON... transition booklet	Used for all CF patients at our center and presented on a state, national and international level	PPC	
Asked local family	BPD booklet revisions	Family reviewed the booklet and made recommendations	PPC	

<b>CURRENT PLANNING/ RECRUITMENT</b>  Brochures, posters, mailing and word of mouth	UWHC Family involvement committee	Group that is currently being recruited/organized		
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### Wisconsin

1. *What do you view as your strongest area(s) of family involvement?*

Family as faculty

2. *For each area, (discussing only one area is fine, but please identify and discuss at least one) please give a brief descriptive narrative about how you developed this aspect of family involvement. Please include:*

*a. Chronological narrative (what happened, in what general order)*

When the Wisconsin Pediatric Pulmonary course was held in a traditional face to face format, various families were asked to come to class to describe their experiences. The family was usually approached by the social worker and the class discussion was facilitated by the nurse. When the course changed to an on-line course, we developed a video of both parents from one family. The Pediatric Pulmonary Center social worker and nurse developed the script. The interview was directed by an instructional designer. In addition to having students watch the video, these parents now lead a one week on-line discussion with the students. This family module, regarding a family's perspective of transition, is consistently one of the highest rated course activities, as indicated by student evaluations.

*b. Barriers that got in the way*

- 1) Identifying the patient(s)/family(ies).
- 2) Determining the content of the video, while limiting the video to 40 minutes in length.
- 3) Obtaining access to the online course for the parents.

*c. If barriers were overcome, how did this happen?*

- 1) We initially shot 4 hrs of video. Many hours were spent editing the 4 hour interview down to 40 minutes.
- 2) The family needed a computer and internet access, which they obtained on their own, for on-line interaction. The University technical support department was contacted to provide the family with needed access to the course (as faculty).



d. *If barriers have not been overcome, how does this impact the family involvement?*

The barriers have been overcome. This family looks forward to their interaction with the students and are eager to share their story. They now post current pictures of their family and share current family experiences in addition to discussing their family's issues regarding caring for their two children with complex medical needs.

e. *Did you utilize specific resources? If so, what were they? Would you recommend these to others?*

We produced the video with the technical assistance of the University of Wisconsin Dolt team, and the School of Nursing AudioVisual team. We worked with the UW computer support services to provide the parents with access to the course.

f. *What else, if anything, was particularly helpful as you were developing this aspect of family involvement?*

Finding a family who wanted: to share their experiences, to help teach health care professionals, and to help support other families with children with special health care needs. Also, developing the encounter in a way that ensures the family feels the encounter is worthwhile and productive.

g. *What advice would you give other training programs who are trying to develop their family involvement in this area?*

Determine your goals and consider what resources are available to help accomplish your goals. Making a video is very time intensive and requires personnel and equipment.

h. *How is your family involvement funded (or, is it not funded)?*

The University of Wisconsin family as faculty project is funded through PPC grant funds. The family is paid each semester for their participation.

**PPC FAMILY INVOLVEMENT IN TRAINING-CURRENT PROGRESS  
CENTER: UAB**

**DATE: 2006**

<b>WHO</b> <b>How recruited</b> <b>Length of time</b> <b>Objective</b>	<b>WHAT-Activities</b>	<b>OUTCOME MEASURES/ EVALUATION</b>	<b>RESOURCES</b>	<b>COMMENTS</b>
Parent Consultants How recruited: through PPC faculty with input from health professionals in the Pulmonary Division. Length of time: since 1999 Objectives: to enhance the family/professional partnership at all levels of the PPC training program.	<ul style="list-style-type: none"> <li>• Orientation to role as Parent Consultant</li> <li>• Annual face-to-face meetings</li> <li>• Communication through mailings, phone calls, and e-mails throughout the year</li> <li>• Provide input into all aspects of training program.</li> </ul>	<ul style="list-style-type: none"> <li>• Parent Consultants rate the PPC on the Family Participation Performance Measure for MCHB.</li> </ul>	<ul style="list-style-type: none"> <li>• Parents are paid a consultant fee and are reimbursed for travel related expenses through PPC funds.</li> </ul>	<ul style="list-style-type: none"> <li>• Parent Consultants are selected to represent the race/ethnicity of patient population served; Parent Consultants also represent parents of children with different pulmonary diagnoses.</li> </ul>
Parents as members of the PPC State Advisory Committee How recruited: through PPC faculty Length of time: since 1995 Objectives: to assist with the planning, implementation, and evaluation of all aspects of the PPC training program; Committee includes 2 parents of children with special health care needs.	<ul style="list-style-type: none"> <li>• Annual face-to-face meetings</li> <li>• Communication through mailings, phone calls, and e-mails throughout the year</li> <li>• Provide input into all aspects of training program, including trainee recruitment and reviewing trainee evaluation of the program.</li> </ul>		<ul style="list-style-type: none"> <li>• PPC funds/resources are used to sponsor annual meeting and for committee communications.</li> </ul>	<ul style="list-style-type: none"> <li>• One parent is the State Coordinator, Family Voices and the State Parent Coordinator for Children's Rehabilitation Service for the State of AL; one parent is the Consumer Coordinator for the LEND program at UAB.</li> </ul>
Family Case Study/PPC Leadership Practicum How recruited: through PPC faculty Length of time: since 2000 Objectives: to provide PPC	<ul style="list-style-type: none"> <li>• PPC trainees work with a family/patient of a culture different from their own</li> <li>• PPC trainees make home visit and</li> </ul>	<ul style="list-style-type: none"> <li>• PPC Trainee evaluations</li> </ul>	<ul style="list-style-type: none"> <li>• PPC funds trainee travel to make home visits.</li> </ul>	<ul style="list-style-type: none"> <li>• Based on previous trainees' feedback, this experience is one of the most valuable to trainees.</li> </ul>

trainees with a learning experience that provides increased awareness of concrete details of day-to-day life with a CYSHCN.	accompany patient/family to a community-based provider.			
Parents as teachers of PPC didactic classes How recruited: through PPC faculty Length of time: since 1995 Objectives: to present parents' perspective.	<ul style="list-style-type: none"> <li>Parents teach a class on Family-Centered Care and one on Family Advocacy in Health Care Policy.</li> </ul>	<ul style="list-style-type: none"> <li>PPC Trainee evaluations</li> </ul>	<ul style="list-style-type: none"> <li>PPC</li> </ul>	
Parents as presenters at continuing education events How recruited: through Pulmonary Division Medical faculty Length of time: May 2006 Objectives: to present parent's perspective	<ul style="list-style-type: none"> <li>Parent of a child with narcolepsy co-presented with PPC medical faculty member during a regional continuing education event, Pediatric Sleep Disorders, Memphis, TN, May 13, 2006.</li> </ul>	<ul style="list-style-type: none"> <li>Participants' evaluations</li> </ul>	<ul style="list-style-type: none"> <li>PPC provided honorarium and reimbursed for travel expenses.</li> </ul>	<ul style="list-style-type: none"> <li>Next time, would like to include parent as a planning committee member of the continuing education event.</li> </ul>
CURRENT PLANNING/ RECRUITMENT  Include more parents as teachers of didactic classes				This was a recommendation from our Parent Consultants; they recommended including a parent of a child when a specific pulmonary disease is presented; we are considering this for the fall semester.
Include parents on planning committees of continuing education events.				
Involve parents in trainees' research projects.				