

NEDA 2008 Conference Report:

Monday, September 22, 2008
Austin, TX, USA

Dear F.E.A.S.T. members and friends,

I got in last night at midnight from Austin Texas, where I represented F.E.A.S.T. at the National Eating Disorders Association annual conference. What a fascinating, productive, BUSY, emotional, and sleepless week!

I arrived to the Austin Renaissance Hotel on Wednesday afternoon, my luggage overstuffed with brochures and materials for our exhibitor table. The hotel was lovely, and my room had a balcony over the many-story atrium.

My fellow F.E.A.S.T. Parent Council member, Chris, and I strategized and set some goals over dinner - as people began to arrive from all over the country for the conference and the hotel started to set things up.

On Thursday morning, I had the honor of meeting Denise, a longtime member of the Around the Dinner Table community. We did a tour of the exhibitor's space and went to breakfast, where we met up with Chris. The three of us took off on foot to the grocery store to buy supplies for the F.E.A.S.T. table: flowers, chocolate, rolls. We felt a bit like high-schoolers doing a home-economics project, and if so I promise we would have gotten the best grade in the class.

Then back to the hotel to set up the table. Thank goodness for Denise: she set to work immediately creating an attractive, functional, and well-composed tableaux. The table featured a basket of dinner rolls, and a sign that said "What 'roles' do parents play in eating disorder recovery." This visual pun was a great hit throughout the conference, and we got parents to write different roles on ribbons which we put on the rolls with heart-shaped pins.

Too soon, we had an exhibitor's meeting, and the first of many times during the week I heard "F.E.A.S.T." mentioned from the podium.

NEDA's Family Welcome reception at 5pm was a great time to reconnect with so many of the people in the ED world that I admire and enjoy - and the great joy of meeting parents I had only 'met' online, like Sandra and Anna as well as longtime NEDA community friends like Joan and M.B. F.E.A.S.T. members and advisors handed out invitations to the F.E.A.S.T. event that evening, and we all got a feel for what a NEDA event does: brings together families and clinicians and researchers and all those concerned with eating disorders.

At 6:30 it was time for F.E.A.S.T.'s dinner - and I confess I was very nervous beforehand. The room was offered to us free of charge by NEDA, for which we are deeply grateful. We set up a welcome table with a slideshow of F.E.A.S.T. information, quotes, and photographs members sent of their families and children and the siblings of patients. Our F.E.A.S.T.

Family Recipe Book was also a star. The hotel set up a fantastic spread of the "Box Dinners" we ordered, and drinks.

Lots of people stopped by the reception to say hi as they went off to other events. We were honored to get a visit from Tracy Kahlo of NEDA, Doug Bunnell from Renfrew, Susan Ringwood from Beat, and Judy Banker from AED. We also met Lorri Benson, the mother and co-author of *Distorted*, a new book from a family perspective.

The tables in the room were set up "classroom style," but we pushed them together into one long FEAST table, where lively discussions went on into the night among the 30 or so who stayed for dinner. Among them, Dr. Walter Kaye's team from UCSD, our Advisory Panel members Dr. Stephanie Millstein and Dr. Cynthia Bulik. We also welcomed Dr. Pamela Carlton, Roberta Katz, and Gail Kennedy. Two special guests, Carrie and Cindy Arnold, were there. Carrie is F.E.A.S.T.'s science blogger and the author of two books about eating disorders and her own recovery process. I like to think I head the Arnold Family Fan Club, but I'm sure I'd have to get in line. The maintenance crew for the hotel finally hovered close enough for us to realize we'd overstayed our time allotment and much of the party repaired to the atrium lounge for further conversation and a nightcap... or two.

Friday was the first official day of the conference, and many people didn't arrive until then. The opening session featured a talk that started some lively conversation afterward: although some parents appreciated the emphasis on nutritional health early in the presentation I would not be honest if I did not also say that there was dismay at an emphasis on some ideas about parents and metaphor that some families in the F.E.A.S.T. community found disheartening. I found myself reassuring parents new to the ED conference environment that while we remain without consensus in the profession on etiology and science of treatment we cannot expect a consistent voice. I assured them that the diversity of views was also reflected in the presentations throughout the event. Throughout the sessions I heard from parents about that wide disparity between different speakers in terms of what the illness is, how it can be successfully treated, and the role of families. And although there were sessions that parents reported feeling angered or dismayed by, this was balanced quite wonderfully by other sessions. Of the latter, more positive feedback came from the presentation by (FEAST Advisor) Stephanie Millstein and Laura Fishman, and there was universal praise for the final session with Jim Lock and Walt Kaye who both brought participants up to date on research and treatment to a very appreciative audience with excellent and engaged questions afterward.

Also on Friday, Lauren arrived - and became part of our merry band. And we met Shelly, at her first ED event and ready to reach out to help other parents. Lauren's daughter is recovering at the age of 10. Shelly's daughter lost her life three years ago. Lauren and Shelly represent some of the spectrum of families who regardless of circumstances come to both receive support but also to give to others. That, to me, is what the parent community does best and in a distinct way from other parts of the ED world.

Friday night, a large group of parents and others in the ED world got out into Austin for the pleasures of barbecue and a "dueling piano bar." Again, lively conversation at the atrium lounge afterward and I am especially delighted with a conversation with Buddy Howard that, yes, kept us up until 2am. I blamed Buddy for both my headache AND my optimism the

next morning - I really think conversation is the way to press forward the issues and controversies in this illness.

Saturday was again a whirl. The day began with a general session where I had the somewhat surreal experience of seeing my 3 minute film "Do Parents Cause Eating Disorders" screened by presenters Judith Banker and Susan Ringwood during their wonderful and optimistic presentation on what parents need to know. It seemed to be well-received, and having come from the experience of attending conferences and reading ED literature and feeling parents were routinely marginalized and blamed and treated with disdain - having that up there was - I am not exaggerating - one of the happiest moments of my life. Sure, we still have a ways to go, but I see so much progress. F.E.A.S.T. members: we are making a difference. My sincere gratitude to Judith Banker, and to NEDA, for letting the parents in the audience feel validated and cared for in this way.

The F.E.A.S.T. table, I must tell you, was almost always busy. I had imagined down time, slow moments, checking my email every once in a while... I was wrong. Thank goodness for Lydia and Bridget for being in charge of the "Around the Dinner Table" forum all week while I was out of touch. We had many visitors, much interest, handed out LOTS of brochures, learned a lot about different clinicians and clinics, met new parents. There was too little time to discuss things, to show off the website, to show off the binder of materials that Chris had prepared (I've linked to an index of that binder from several places on the F.E.A.S.T. site - it is the most comprehensive bibliography - with web links - of the best literature on the current science and thinking on EDs.)

The biggest hit? The FEAST Family Recipe book. I'm sure there were those who were offended by our emphasis on food and on (horrors!) high-calorie food, but we made it a point to not be afraid of this issue. In fact, Denise had the forethought to bring butter boxes for our display. And the chocolate kisses were a hit - thank you, Sarah. There is an irony, somewhere, that the eating disorder world remains wary of pictures of food, of eating, of bodies. Few of the visual images of the displays of other exhibitors show people and when they do - the bodies are lower than average size. When I told our Parent Council that having food on our table would be controversial their answer was that I should have full meals delivered to the table by a waiter every few hours... I declined that idea on the basis of practicality, but the "roles/rolls" and the butter and the chocolate and the many delicious images of food and real families on our slideshow were, I hope, in the spirit of FEAST's embrace of the issue.

Funny story, and one that pretty much sums up the F.E.A.S.T. community. While Chris and I were upstairs taking the opportunity to discuss some concerns about the NEDA Toolkit content with a NEDA board member, a bit of a crisis was going on downstairs. I was only gone for 30 minutes, but I returned to the exhibitor hall to find Everything Gone. The booths, the tables, the people.... and everything on and under and around the F.E.A.S.T. table. Being naive about the range of time for breakdown, I was entirely unaware that the room - like a movie set - could be reduced to an empty hall in that span of time.

I literally doubted my sanity as I went from one maintenance worker to the other with visions of all our stuff in a dumpster. Alternately, I pictured my kind and generous volunteers who had been at the table thinking I had gone off for margarita and

thoughtlessly left them to figure things out. When I finally found some friends who explained that the parents had boxed everything up and brought it to their rooms I did what any sane person would do: I burst into tears for a while before I started laughing. And I still am. My sincere, fulsome, admiring thanks to Anna and Denise and whoever else was there - and to Joan and Mary Beth for taking care of me - and the UCSD staff who helped - you are all my heroes. And NEXT year, I won't schedule any meetings during break-down!

And another quick anecdote about the power of 'being there' and patience.. Years ago, I was asked to leave the Something Fishy online forum for parents. I had, apparently, said once too often that parents don't cause eating disorders and that EDs are a brain disorder - shocking stuff in 2003. Over the years I've become friendly with people involved with the site and many of the participants. In person, it is really hard to remain angry about that. And I like to think it grows harder for people who have objected to my message (parents are part of the solution, not the problem) over the years to continue to see me year after year without noticing that I really am just a normal mom and of no threat to anyone or thing. I asked the SF moderator last night to stop blocking mention of me or my book on the site. She said yes. I am grateful!

My sincere thanks to everyone who made this trip possible, affordable, and productive. I apologize for missing particular details or names - I'm sleep deprived and a bit giddy.

I leave you with some pictures, and gratitude, and a big smile on my face,
Laura