

PURSuing PERFECTION IN HEALTH CARE

Involving Patients in Redesigning Care

Parts 1 & 2 – Final Script - 11/8/04

VIDEO

Sound up, Blackwelder family at home.

CG: The Blackwelder Family

AUDIO

Tracey Blackwelder

We have seven kids. Three of our kids have cystic fibrosis.

NARRATION

CYSTIC FIBROSIS, CF, IS A PROGRESSIVE, FATAL DISEASE THAT AFFECTS A CHILD'S LUNGS AND PANCREAS, AND REQUIRES EXTENSIVE HOME TREATMENTS. THERE IS CURRENTLY NO CURE.

Sound up Tracey talking with her kids, sound under

**CG:
Tracey Blackwelder
Parent**

Tracey Blackwelder

One of my sons takes a treatment once a day. He's breathing in some medication that goes into the lungs, loosens up the mucous. After that breathing treatment he has CPT, which is physical therapy for the chest. We're kind of knocking the walls of his lungs, loosening up the mucous so he can cough. My daughter Tess is 3 and because of CF she doesn't gain weight very well.

Sound up Tracey with Tess, sound under

Tracey Blackwelder

As a last resort the doctor suggested putting in the G-tube so at breakfast, lunch and dinner after she eats we give her about 90cc's of this high calorie formula. We've gotta get some weight on her. We don't want to pressure her, but there is that in the back of my mind: she's got to eat, she's got to eat, she's got to eat.

CG: The Lang Family

Sound up Lang family arrives at the hospital, sound under

Jim Lang

The disease itself is a nasty, nasty, nasty disease. People come up and say, “Jim, how are the kids doing?” and I usually say every breath they take is killing ‘em.

NARRATION

MANY CHILDREN WITH CF MUST BE HOSPITALIZED EVERY FEW MONTHS FOR MORE INTENSIVE TREATMENTS. PARENTS DEPEND ON THE HEALTH CARE SYSTEM TO PROVIDE THE SAME QUALITY OF CARE THEIR CHILDREN RECEIVE AT HOME.

Sound up Jim and nurse discuss medication, sound under

**CG:
Jim Lang
Parent**

Jim Lang

This morning when I came in I asked to make sure she got the right medication and she didn’t.

Sound up Jim and doctor discuss system, sound under

Jim Lang

I’m not blaming the doctor. I’m not blaming the nurse. It’s just the way the system’s set up and we have to do some workarounds sometimes with the system the way it currently is.

CG: The Schindler Family

Sound up Terri and nurse, sound under

CG:
Terri Schindler
Nutritionist
Cincinnati Children's Hospital Medical Center

Terri Schindler
 I don't feel my daughter's safe when I bring her here for multiple reasons. Not only, you know, medication errors, but infection control type of issues. I can't think of one time that she's been in the hospital where there hasn't been some mistake that's happened. I was very fortunate in that I work here. And I was able to call my co-workers and tell them that something was wrong, and they were able to intervene. And it makes me feel terrible that I know that other people that don't have the position that I have, wouldn't have access to that like I do. And couldn't have intervened like I could. And it shouldn't be that way.

CG:
Dr. Jim Acton
Director, Cystic Fibrosis Center
Cincinnati Children's Hospital Medical Center

Dr. Jim Acton
 How do we get to where we don't have defects or flaws? The first step is obviously admitting or acknowledging that we have them. That we aren't perfect. That there may be better ways to do what we're doing.

NARRATION

CINCINNATI CHILDREN'S HOSPITAL IS AN INTERNATIONALLY RENOWNED PEDIATRIC MEDICAL CENTER. CONCERNED ABOUT CLINICAL OUTCOMES FOR CF PATIENTS, THE INSTITUTION HAS EMBARKED ON AN AMBITIOUS REDESIGN OF BOTH INPATIENT AND OUTPATIENT CARE.

CG:
Gerry Pandzik
Organization Development Consultant
Cincinnati Children's Hospital Medical Center

Gerry Pandzik
 The design team really started out like traditional design teams start out. Some discussion around, should we have an advisory group that then we'll come up with all the fabulous ideas, and then we'll say, "Wouldn't you want this?" to the families or ask them to say whether or not we're on the right track. And that conversation over time evolved into it just makes more sense to have families at the table. And once that word was said, it was maybe a transforming moment when you think about it. Why wouldn't we just have families here and people started to think through what are the implications of that?

Jim Acton

We were worried what response they would have to hearing that we didn't have the best lung function. We didn't have the best nutritional status. We didn't have the best outcomes in C.F. care. We were worried that they may respond with some anger that perhaps their child might be healthier right now if they had been somewhere else. We were worried that they would respond with a desire to leave, to go somewhere else, to find better health care.

Tracey Blackwelder

It seems like a no-brainer. You know why wouldn't you involve families and patients? And I don't know why it's taken so long.

Dissolve to the CF Core Team Meeting.

**CG:
CF Core Team Meeting**

NARRATOR

THE HOSPITAL HAS TAKEN THE UNPRECEDENTED STEP OF WORKING DIRECTLY WITH PARENTS – IN AN ONGOING EFFORT – TO REDESIGN BOTH THE INPATIENT AND OUTPATIENT CARE OF THEIR CHILDREN.

Sound up Terri speaking at the Core Team Meeting, sound underJim Acton

They rolled up their sleeves, they told us that not only did they support what we were doing in providing their children's health care, but they wanted to help us make it better.

Sound up Dr. Acton and Tracey Blackwelder speak at the Core Team Meeting, sound underTracey Blackwelder

You're actually involved with the group, which is a major change for our family. And I'm not afraid to ask, which maybe before I was. I think that the doctors and the nurses have learned how to involve families that way so that we don't feel intimidated.

**CG:
Honor Page
Parent**

Sound up Honor Page speaks at the Core Team Meeting, sound under

CG:
Lee Carter
Chairman, Board of Trustees
Cincinnati Children's Hospital Medical
Center

Gerry Pandzik

We've opened a Pandora's box in a way, okay? They're not going to tolerate certain things in health care the way they did because they've learned to expect something different. That raises the bar in terms of you've got to be willing to follow through.

Lee Carter

Our vision at Children's Hospital is we will be the leader in improving child's health. There is nothing that will recognize that vision faster than if we can change the way medicine is delivered in this country, and help change it. But the changes are going to come from people in this room, not from the 6th floor of this hospital. And we know that.

Sound up Tracey with Dr. Chini, then sound under

Jim Acton

I don't think any of us really have that picture of what the perfect health care is going to be like. I think our patients and families have good ideas of what they would like it to be. And I think they're learning with us.

NARRATION

EMPOWERING FAMILIES TO HELP REDESIGN MEDICAL DELIVERY SYSTEMS IS A MAJOR TRANSFORMATION FOR ANY HEALTH CARE INSTITUTION. FOR CINCINNATI CHILDREN'S HOSPITAL, IT IS THE ESSENTIAL FIRST STEP IN THE JOURNEY TO IMPROVE THE QUALITY OF LIFE AND INCREASE THE LIFESPAN OF CHILDREN WITH CYSTIC FIBROSIS.

Tracey Blackwelder

Life expectancy, I try not to think about too much. And in our family, it's kind of a touchy subject. The other kids, even though they're small, they know. And maybe that's another reason why they help out so much with each other. I think it eases their fears.

Jim Lang

If we don't see results our time is being wasted, where we could have more time to be home with our kids that might die within a few years, you know. We want to keep them alive as long as possible. We want them to have the best health care that we can and some of us have made the decision to help as much as possible to get a better health care system. And if the health care system doesn't want our help, I don't want to waste our time.

FADE OUT SOUND AND PICTURE

PART 2**VIDEO**

CG:
Jim Lang
Parent

CG:
Dr. Jim Acton
Director, Cystic Fibrosis Center
Cincinnati Children's Hospital Medical
Center

AUDIO

Jim Lang
 When my children were first diagnosed with Cystic Fibrosis eight years ago, the parents' voice wasn't heard. It was just rattle, noise in the background. Now I think they're listening. They're listening to what we have to say. And they're using what we have to say to improve health care.

Jim Acton
 Having parents participating with us side by side on this project has not only had a tremendous impact on how our quality improvement has played out, it also has had a significant impact in my practice personally and I think that I've seen similar changes in my colleagues. The changes that I've seen in my practice have been around my comfort level, my ease and I think in some ways my ability to collaborate with the families of my patients, to work with them as an active partner in taking care of their children's CF.

NARRATION

SINCE 2002, THE REDESIGN TEAM OF PROVIDERS, PATIENTS AND FAMILIES HAS INSTITUTED A NUMBER OF SIGNIFICANT PROCESS IMPROVEMENTS. IN THE OUTPATIENT CLINIC, VISITS HAVE BEEN REDESIGNED TO BE MORE COLLABORATIVE IN NATURE.

CG:
Tracey Blackwelder
Parent

Tracey Blackwelder

I remember the way it was where I was just told what to do. And I respect those physicians, so I'll do whatever they say, but now the role has switched in that it's a decision that we've made together, and she also includes our children in that like my son Brent, who's 12. And I appreciate that. I think she's also teaching my child self-management skills. It's definitely a shift for the better. I mean, how exciting is it to have your doctor ask your opinion?

Sound up Dr. Chini talks with Blackwelders, then sound under

NARRATION

EVEN MORE DRAMATIC CHANGES HAVE BEEN INSTITUTED IN THE HOSPITAL'S CF UNIT. PATIENTS AND THEIR FAMILIES ARE ENCOURAGED TO TAKE A MUCH MORE ACTIVE ROLE IN MAKING CRUCIAL DECISIONS ABOUT THEIR OWN CARE.

Sound up Dr. Chini and Terra discuss procedure, then sound under

CG:
Dr. Barbara Chini
Division of Pulmonary Medicine
Cincinnati Children's Hospital Medical Center

Dr. Chini

There's definitely been a change in attitude here at Cincinnati Children's Hospital, where the patient is really presented with the options for his or her care and is the decision maker. And even a child who is less than 18 often is the decision maker.

CG:
Terra Studer
CF Patient

Sound up Dr. Chini and Terra continue consult, then sound under

Dr. Chini

What happened today in this patient's room is really what happens on a daily basis over and over. This is their body. They get to decide what does or doesn't happen to it. I honestly do not feel any threat to my ego or medical degree or experiences. I feel that my role has shifted from being the ultimate decision maker, to being the provider of information, education, options, and helping them to make the best decision possible. But what they say goes.

NARRATION

PATIENTS AND FAMILIES ARE NOW MORE DIRECTLY INVOLVED IN MAKING THEIR OWN CARE DECISIONS. BUT ADJUSTING TO THIS MAJOR CULTURAL CHANGE HAS BEEN A CHALLENGE FOR MANY STAFF MEMBERS.

CG:
Gerry Pandzik
Organization Development Consultant
Cincinnati Children's Hospital Medical
Center

Gerry Pandzik

We watch with raw emotion when families talk about an experience that wasn't ideal. And we cannot only relate to that in our own personal experiences, but our families tell us the stories. And that's not easy to hear sometimes. But without that, we wouldn't be able to make the changes that we've been able to make.

Tracey Blackwelder

I think all of our eyes have been opened in different ways, which is a good thing. I think for the physicians and the staff, their eyes are opened into what's important for us. And we're able to realize how much work is going into this. But I don't know if they always see it the same way as a parent does, and that's why it's important that we work together as a team. We have that little fire that we can ignite within them that yes, we've got to keep going, keep going.

CG:
Jeanne Weiland
CF Clinical Nurse Specialist
Cincinnati Children's Hospital Medical
Center

Jeanne Weiland

We really can't make effective change unless the families are partners with us in this process, because the changes need to be based on what is important to them, and in the past it's always been what we think is important to them, and so I've learned that we really need to incorporate their voice in everything that we do, every decision we make.

NARRATION

IN ORDER TO IMPROVE CLINICAL OUTCOMES FOR CF PATIENTS, THE REDESIGN TEAM DECIDED TO GO OUTSIDE THE INSTITUTION TO LEARN FROM THE TOP CF CENTERS IN THE COUNTRY. BUT AT THE TIME, THE CYSTIC FIBROSIS FOUNDATION, WHICH COLLECTS OUTCOMES DATA FOR THE NATION'S CF CENTERS, HAD A POLICY AGAINST SHARING THE INFORMATION. THE TEAM MET WITH FOUNDATION REPRESENTATIVES.

Sound up Honor Page speaking at meeting then sound under

CG:
Honor Page
Parent

Honor Page

I can see where transparency would cause a lot of fear both on the side of the caregivers and the side of the families and patients, because it's really addressing where there might be some flaws, and also where there are some successes. But, it's that fear of am I at the best place for my daughter's care? I think by not sharing your data, you do appear to have something that you're fearful of.

CG:
Dr. Bruce Marshall / Dr. Preston
Campbell
Cystic Fibrosis Foundation

Sound up Jim Lang at the meeting then sound under

NARRATION

AFTER A CONCERTED EFFORT INVOLVING A NUMBER OF DIFFERENT ORGANIZATIONS, THE FOUNDATION AGREED TO HELP CINCINNATI CHILDREN'S CONTACT THE CF CENTERS WITH THE BEST OUTCOMES. PARENTS AND PROVIDERS CONDUCTED A BENCHMARKING VISIT TO FAIRVIEW-UNIVERSITY CHILDREN'S HOSPITAL IN MINNEAPOLIS.

Sound up Honor at benchmarking visit, then sound under

Honor Page

What I do think is terrific about sharing this data is, there gets to be a picture perhaps across the country of where children and young adults might be doing better, and what can we learn from that? What can we take away from these centers and share amongst everyone? And transparency is essential for that to happen.

Jim Acton

Not only is transparency a critical piece of quality improvement, but one of the things that we're learning here is that transparency is also a very integral piece of providing care for chronically ill children.

Sound up Dr. Acton talking with Dr. Milla, then sound under

CG:
Dr. Carlos Milla
Director
University of Minnesota CF Center

Jim Acton (continued)

Everybody needs to have the information at the time they need it and they need to have the tools to act on that information. That's the definition of transparency.

CG:
Jim Anderson
Chief Executive Officer
Cincinnati Children's Hospital Medical Center

Jim Anderson

We've embraced the concept of transparency on an intellectual level, and experienced all the kinds of anxieties when it rears its sometimes not very attractive head.

CG:
Victor Needham
Parent

Sound up Victor Needham at General Pediatrics meeting then sound under

CG:
General Pediatrics Morning Report

Jim Anderson (continued)
 We view it as a very important tool for motivating us and driving us to continue transformation and to continue the very hard work of looking at our behaviors and dissecting our systems and putting them back together in a new and creative way and embracing new ways of doing things.

CG:
Jeanne Hime
Parent

Sound up Jeanne Hime at General Pediatric meeting, then sound under

NARRATION

TRANSPARENCY IS JUST ONE OF A NUMBER OF ISSUES THAT PATIENTS, PARENTS AND PROVIDERS ARE STARTING TO ADDRESS AS THEY WORK TOGETHER TO IMPROVE OUTCOMES FOR THOSE WITH CYSTIC FIBROSIS. FOR CINCINNATI CHILDREN'S HOSPITAL MEDICAL CENTER, INVOLVING PATIENTS AND FAMILIES IN REDESIGN EFFORTS IS ONLY ONE OF THE MANY WAYS THE ORGANIZATION IS BECOMING MORE PATIENT-CENTERED IN THE CARE THAT IT PROVIDES.

Honor Page

I think the change that this project brings to Children's is more than just process and approach, but perhaps a cultural change. Parents and patients actually sitting at the table and saying what they feel and sharing their ideas, and it really is a coming together of ideas where we don't really feel like we're on opposite sides of a team. We feel like we're working together for the best outcome for our children.

Tracey Blackwelder

For my daughter Tess ... she goes through so many things, so many intense, hurtful procedures that have to be done that's heartbreaking. And so for me right now, the most important thing is quality of life. And I think by making changes at Children's, that is going to happen. And it's very exciting. I know it's gonna happen.

FADE OUT SOUND AND PICTURE