

Lung Center Learning History

Organizations like ours try to learn from our experiences, both the successful and the not-so-successful ones. This is a way of assessing our effectiveness and sharing information. It is an important process for the growth of any organization. In doing so, we have recorded some of our learning process around the concept of a “learning history.”

We went back to the source of our Lung Center program -- the people who saw what it might become, those who formed the process for driving the program, and those who helped to implement and manage it. We tried to capture and convey the experience and insights of these people. The result of this new form of assessment, a Learning History, is put forth on the pages that follow. We believe that what we have learned can help you think about the best way to reach lung disease sufferers in your community.

We hope that this learning history will give you a chance to catch your breath and explore new ideas. As the ALA-I Lung Center continues to try and make a place for itself in our community, we hope our challenges and triumphs will be events that communities beyond our walls can learn from too.

Memorial Health System staff members are more than happy to answer any questions you may have regarding this process. Feel free to call us at (219)284-7115.

Phil Newbold
CEO, Memorial Hospital/Health System

First Breaths

In many ways, the American Lung Association of Indiana Lung Center is still gasping for air. A joint project of the American Lung Association of Indiana (ALA-I) and Memorial Hospital of South Bend, the program is a pilot for the state. Opened in the fall of 1998, it's planners

Tobacco

- ✘ 6,200 children die each year in the United States due to exposure to tobacco smoke.
- ✘ Indiana ranks second highest in smoking among the 50 states.
- ✘ Smoking kills approximately 27 Hoosiers each day.

unanimously agree that more work lies ahead than behind them. Yet, looking to past ALA-I Lung Center accomplishments does provide a framework for present and future challenges.

American Lung Association of Indiana Lung Center

Serving the Public and the Health Community with Patient Education, Disease Prevention, and Asthma Management as Prescribed by Your Physician.

The American Lung Association of Indiana Lung Center seeks to improve the quality of life and decrease suffering for children, teens and adults with lung disorders through education, support programs, and disease management.

From the ALA-I Lung Center program brochure.

“It started about two years ago, when we recognized that we were having a hard time as an organization really impacting the lives of people who have asthma,” says Dick Beall, Executive Director of the American Lung Association, Region I, “Someone asked if there wasn’t a way that we could really get on top of this problem. You know there are a lot of people who have asthma,” he continues emphatically, “It’s increasing in incidence every year. The World Health Organization sees it as a world-wide epidemic. And, for the most part, patients are not necessarily managing themselves well.”

Indeed, in Indiana alone over 320, 000 people suffer from asthma (American Lung Association). One-third of those are children. Three times that many residents deal with some sort of lung disease. Many of us look to statistics like these to give us an idea of the impact of lung disease in our communities, but the numbers themselves can’t provide us with an idea of what lung disease sufferers truly experience.

Dick Beall can. With a box of cocktail straws in hand, he might offer an office visitor an experience that simulates some of the effects of lung disease. Encouraging you to close your mouth tightly around the straw, plug your nose, and try to breath, he watches and says “Now, that’s a very mild case.”

“People with asthma,” he elaborates, “even if they’re doing well and feel good, still carry a degree of inflammation in their bronchial tubes. If you limp because you hurt your foot, you notice the limp for a couple of days -- but after a couple of years you’ve become adjusted to limping. So, if you have trouble breathing, you notice it right away. But after a few years you adjust. You walk

little slower, you stoop a little bit more. If you're a kid, you don't got out for sports, you don't play outside, you watch a lot of TV. You become a different kind of person. So, for the severe episodes, [asthma sufferers] pop into the emergency rooms, or they pop into their doctors' offices. They're treated on an emergency basis and they feel better, but even when they feel better they're not really what a normal breather is, but they get used to it...There's a difference between chronic and acute. When you have cancer, you act quickly because there is incredible urgency to do something today. With chronic diseases people just live a very low quality of life."

The ALA -I Lung Center was created with the idea of improving life quality for lung disease sufferers in mind. Dick says that when asthma patients have an "episode" -- a severe, sometimes life-threatening attack, they are likely to seek emergency medical services and then return home once they feel better. "What we try to do is to stop these episodes from even happening."

The Center's beginning stemmed from an already established connection between the American Lung Association of Indiana and Memorial Hospital. Pat Wise, RRT, Director of Pulmonary Services at Memorial Hospital was a long-time supporter and Board member of the American Lung Association. As Dick was formulating the Lung Center idea, Pat was a person he sought out for input. "Dick had a vision of educational opportunity and partnership with the hospital," says Pat.

The ALA-I Lung Center was designed to:

- ✦ Give patients the skills needed to manage their asthma;
- ✦ Reduce the debilitating loss of life due to asthma and other lung diseases;
- ✦ Provide smoking cessation to adults and teenagers, and;
- ✦ Cut health care costs.

Curriculum developed for use in the ALA-I Lung Center includes these goals:

- ✦ Increase patient compliance;
- ✦ Reduce emergency room visits and hospital stays, and;
- ✦ Increase physician productivity and effectiveness.

The vision has become a reality with the development of the American Lung Association of Indiana Lung Center, in partnership with Memorial Hospital. A building and staff have been devoted to the Center, and programs are in place. Yet, as the program's developers have realized -- this is just the beginning.

No Hot Air: Start-Up and Programming

Reg Wagle, Memorial Health Foundation Vice President, was involved in some of the earliest discussions about the Lung Center initiative. For Memorial, deciding to get behind the project was also a decision to do something different. “This was a new step in a number of ways,” says Reg, “This was looking at a defined disease population. Most of everything we do in partnering with religious communities, with the schools -- all of those other things that we do -- are generally about a broader population. Here we’re talking about a fairly large population, unfortunately, but a clearly defined one...This was a different path.”

Also, unlike other community projects Memorial had undertaken, this was the first where the hospital partnered with a national organization, rather than a local agency. “We did it mostly because it was going to be an experiment,” says Reg, “and from that experiment we would learn about how we might better improve the quality of life of the particular defined clinical population.”

In 1997, Memorial’s Community Health Action Group [CHAG] decided to take on the Lung Center as a project under Memorial’s tithing policy (see Tithing Learning History). American Lung Association representatives from all over the state offered their support to the program. They agreed that a strong possibility existed for other local Lung Association chapters to establish Lung Centers in their communities, working together with hospital partnership.

Pat found space for the Lung Center in a building that the hospital’s marketing department had recently vacated. A small, separate building from Memorial, it was easily accessible with parking just outside the door. It was the kind of space “that wouldn’t make people feel like they were sick by having to come to the hospital,” Pat says, “but it needed some work” to fit the Lung Center concept. Pat worked to define design changes and remodeling needs for the building, and in the end Memorial put in roughly \$38,000 for changes, repairs, and upgrades.

The ALA-I Lung Center is staffed on a day to day basis by hospital employees. Stephanie McCune, an employee of the American Lung Association, acts as marketer for the Center, the newest position to the initiative. As Rehab Coordinator of the Lung Center, Ken Semonis, RRT, a long-time Memorial employee was excited about moving to the ALA-I Lung Center when the opportunity arose. He has been working to develop programs to use with clients of the Center and the community at large. Whether it’s one-on-one with an asthma patient or out with a church group, Ken puts together age-appropriate sessions for a variety of audiences.

While community awareness grows, the bulk of programming has happened in individual sessions. “I went through some Lung Association materials and then developed a one-on-one asthma teaching program based on their *Open Airways* program. I used that as the guide,” says Ken, “So the first session would be teaching them exactly what asthma is all about, starting with the lung anatomy -- what happens during an asthmatic episode, what some of the triggers can be...and then I make sure that they’re able to use a meter dose inhaler correctly with a spacer device...and then we teach them how to use a peak flow meter as a guide to help them determine how severe their episodes are. That’s the crux of the one on one sessions.”

All of the ALA-I Lung Center’s programs use standards set by the National Institute of Heart, Lungs and Blood [NIHLB] in their curriculum. A set of the American Lung Association’s programs have been adapted for ALA-I Lung Center use, but exactly what programs will turn out to be mainstays of the Center still remain to be seen.

“It’s just all so new and so adaptable,” says Stephanie McCune, Coordinator of Marketing. She emphasizes that any American Lung Association program can be put to use at the Center, and there are many to chose from.. Already, Ken has used existing materials to create one hour community sessions about asthma -- again from the Lung Association’s *Open Airways* program. *Open Airways* features a six lesson interactive curriculum in its original form, focusing on asthma education for elementary school children. Ken has used the program to make shorter versions that fit the needs of ALA-I Lung Center audiences.

Camp Superkids is another Lung Association program that the ALA-I Lung Center now plays a role in. A week-long residential camp for children with moderate to severe asthma, campers learn more about their disease while in the

Programs that are currently, or will be available at the Lung Center:

- ☞ Adult Asthma Education
- ☞ Pediatric Asthma Education
- ☞ Exercise Induced Asthma Education
- ☞ Open Airways Asthma Education
- ☞ C.O.P.D. (Chronic Obstructive Pulmonary Disease)/Emphysema Education
- ☞ Freedom From Smoking/Cessation Programs
- ☞ Teen Smoking Cessation Programs

Other resources and materials available to the community through the Lung Center include:

- ☞ Individualized Asthma Action Plan
- ☞ Lung Disease Prevention Brochures
- ☞ Lung Disease Education Brochures
- ☞ Self-Help and Group Smoking Cessation Materials
- ☞ Disease Management Workbooks
- ☞ Peak Flow Meters
- ☞ Metered Dose Inhalers
- ☞ Spacers for Inhalers

program. This year, Ken will attend *Camp Superkids* as a resource for campers and staff, providing education for both groups. A workshop for older kids is being discussed for Exercise Induced Asthma. Here, teens will be encouraged to learn about asthma and how to manage it as a way to improve athletic performance. The ALA *Freedom From Smoking*, a smoking cessation program, is also operating out of the Center.

A is for Asthma is a program geared for preschoolers. A twenty to twenty-five minute segment, the session features a Sesame Street video for daycare kids and other young populations. *A is for Asthma* was developed by an outside company and later picked up by the ALA-I Lung Center. *Most programs and materials are free of charge with a physician referral.*

Taking a Deep Breath: Challenges

“I felt sure that if we built it, they would come,” says Pat Wise, RRT, Director of Pulmonary Services at Memorial Hospital. As it is, building the ALA-I Lung Center has been less than half the battle. Staff estimate that the Lung Center has seen roughly fifty patients in the five months or so it’s been open.

Pat cites low physician referral as an ongoing issue that’s contributed to the ALA-I Lung Center’s small client rate. From the beginning, the ALA-I Lung Center was not a physician-driven program, and has had to work hard to improve physician understanding about what the Center can offer patients. “We were a little concerned that we’d be seen as a threat,” says Pat. Currently, physician referrals are slowly increasing.

“The message we want to get to physicians is that we want to enhance *your* practice,” says Stephanie McCune, the program’s marketer, “It’ll take a couple well-respected physicians in the community to feel good about us before the ice is truly broken in terms of referrals,” she adds. In large part, Stephanie was hired in April to work on issues just like this one. She and Pat both have spent time contacting local organizations and making community visits to heighten awareness about the programs. Just recently they gained association with the Beds and Britches, Etc. program (see B.A.B.E. Learning History), another Memorial affiliated program that offers new parents coupons for baby merchandise and equipment. Parents receive the coupons only after they complete classes or activities designed to improve their own or their families’ health. The Lung Center can now dispense B.A.B.E. coupons as a part of that health incentive.

Still, some frustration is evident. “What the vision was initially is not what the realities are now,” says Pat, “We’ll do almost anything we can to get to people -- go to churches, social groups...I

don't know how to make this any more successful...The lack of follow-through has been extremely disappointing.”

Dick Beall defines the largest issue the ALA-I Lung Center faces very clearly: “It’s capturing people. The problem we’re having right now is in marketing...It’s like we’re having a party and no one comes except the respiratory therapist and the Lung Association staff, and we’re sitting there twiddling our thumbs and saying, ‘I wonder where the people are.’”

“There’s a lot of denial in chronic disease,” Dick points out, a possible explanation for the low participant rate at the Center. Attending sessions with other lung disease sufferers may be too public for some people. Dick himself admits that he might attend a individual session, but probably not a group class, a large part of the Center’s programming. He points to a culture used to the idea of taking medication to alleviate problems. “We want to be able to take pills to feel good and then we don’t have to go to classes, park, get out, sit in a room with other people who are wheezing and say ‘I don’t know why I’m here.’”

Helping potential ALA-I Lung Center patients realize the connection between a higher quality of life and active participation in Center programs is the real hurdle. Dick says that many patients would invest a lot in alleviating their symptoms and getting more out of life. “We’ve got to find out now how to communicate to them that the Lung Center is a way to work toward becoming symptom free,” he says.

Over the next several months, program staff and partners will assess the progress of the ALA-I Lung Center, an evaluation that may lead to changes, and possibly even discussions about the Center’s survival. He admits “there’s a sense of urgency to get this going,” and Stephanie and Pat concur.

Stephanie, an energetic staff addition, moves back and forth from the American Lung Association office to Memorial to the ALA-I Lung Center, which is located just minutes south of the hospital. An employee of the American Lung Association, she reports to Dick and Pat separately, and claims accountability to both institutions of the partnership. A challenge unique to her position has been acknowledging each partner’s agenda and finding common ground between them. One example of this struggle lies in the different background of collaborators, such as clinical, non-profit, and marketing fields. Stephanie makes a clear distinction between a clinical mind set, where people are often focused on simply “providing a service” and other settings where building community support, drawing people in, and promoting education and involvement are critical. “We all have to blend and mesh, but it just takes time,” she says.

Stephanie's job is linked to the success of the ALA-I Lung Center, and Pat admits that a certain feeling of risk underlies the project for everyone: "We all have something at stake here."

Nevertheless, the American Lung Association has begun to take the first steps in exploring the Lung Center concept in other Association regions as the first ALA-I Lung Center works to build a solid base of support. Dick cautions that hospital involvement is necessary for a program of this sort, and it is simple conversations between the Lung Association and hospitals that have begun in other areas.

These community partnerships could include more than one institution in an area. Pat Wise, RRT, Directory of Pulmonary Services at Memorial, says that from the beginning, the hospital worked to draw in partners, but that joint efforts were slow in coming together. Dick points to a lesson the Lung Association learned by saying, "I think if we were going to do it over again we might have sat down with the other hospitals here and explained to all of them at one time what it is we're trying to do...I think we caused some hurt feelings...That may not be something Memorial is going to be experiencing, but as the Lung Association we have. And when that happens we have to be very open, honest, and straight-forward, by saying: 'We just didn't think. We hope you'll forgive us.' But we also have said that if this thing works we're not going to be exclusive. Every hospital in the state of Indiana that wants a Lung Center ought to have a Lung Center..."

Dick also admits that the hospital partnership hasn't worked quite as neatly as he imagined. "I thought that by working with the hospital we would have just tons of people flow through this thing [the Lung Center]. That hasn't happened. I thought that there are doctors affiliated with Memorial. I thought 'This is just going to be a natural.' It still seems like it should be. I still can't believe that it's not."

Reg Wagle, Memorial Health Foundation Vice President, puts many of these challenges in perspective by emphasizing the value of the process. "Even if fails," he says, "we will have learned." Whether the end result is a Lung Center, or a better idea to address the issue, the direction remains true, though it may be marked by turns. Learning is a critical benefit of trying new things. "People are interested in experimentation in learning with the idea that they may be creating a new model," says Reg, "That's the kind of wonderful risk-taking that we like to be a part of because we know how that excites people."

A Breath of Fresh Air?
Looking Ahead at the ALA-I Lung Center

In the future, the American Lung Association hopes that not only will it have helped to provide a model for other Lung Centers in the state, but that it might offer coordination between Lung Centers. This and other foreseen benefits and roles of the American Lung Association include:

- ∞ Providing statewide coordination for all Lung Center hospitals.
- ∞ Providing standardized training for physician and hospital medical staff.
- ∞ Providing standardized program and curricula for patients based on the National Heart, Lung and Blood Institute Guidelines.
- ∞ Capturing statewide data.
- ∞ Disseminating outcomes.
- ∞ Placing Lung Center Coordinators in Indiana communities to market Lung Centers.
- ∞ Reducing the health costs of managing chronic lung disease to employers, insurers and patients/families.
- ∞ Increasing physician productivity and effectiveness and the compliance rate among patients.
- ∞ Giving easy access to its patient disease management programs in rural and inner-city areas.
- ∞ Linking the new Asthma Clinical Research Center (in the Indiana University School of Medicine) to Lung Centers around the state.
- ∞ Lending its name and imprimatur to hospitals/clinics.

Eighteen sites for ALA-I Lung Centers have been identified in fourteen Indiana cities for future development. The annual budget for each Lung Center from a Lung Association perspective is \$81,400, which includes costs for the personnel the Association provides, equipment, as well as all expenses for training and marketing. The Lung Association has begun work on a capital campaign to fund development of the Lung Centers with a goal of raising \$2.8 million dollars. A marketing plan does, and will continue to assist, in the Center's community visibility and medical networks.

ALA-I Lung Center Marketing Plan

1. Promotional brochures for physicians and patients are completed. There is general agreement that the key to strong patient referral is wide acceptance by primary care physicians. The basic marketing message is that children and adults with chronic lung disease require:

- ⊗ Medical management
- ⊗ Drug therapy
- ⊗ Patient education

The American Lung Association of Indiana Lung Center works with the patient's physician to achieve this education and build personal disease management skills. Knowledge is a powerful medicine©.

2. ALA-I staff will accompany pharmaceutical representatives on physician calls. (The emphasis will be on visiting primary care physicians.) The purpose is to introduce the Lung Center to physicians and give Briefing Breakfasts invitations to the physician's support staff. Note: a disclaimer concerning the ALA non-endorsement of all drugs will be scripted and stated to physicians.

3. Briefing Breakfasts are designed to acquaint the physician's medical and support staff with Lung Centers as well as future training sessions designed for them. The purpose of this training is to enhance physician productivity and achieve greater patient compliance.

4. The ALA-I will establish a local Oversight Committee and invite those physicians who have influence among their peers. The purpose of the Oversight Committee is to communicate the purpose of the Lung Center to the physician community and advise ALA-I on physician concerns and suggestions.

5. Feature articles are planned for The South Bend Tribune and will be submitted to every newspaper in a community targeted for a Lung Center.

6. Presentations will be offered to: Rotary, Kiwanis and other service clubs; senior citizen centers, churches, AARP meetings, bank senior clubs and other groups that address the needs of senior citizens; the general public with such topics as *Asthma Basics for Adults, Living with COPD, and Pediatric Asthma -- What Parents Should Know*.

7. Off-site programs are planned to capture the community's attention and reach additional clients:

∞ Athletes and Asthma Workshop, University of Notre Dame. It is estimated that 70% to 80% of teenagers who have asthma also have exercise induced asthma. The Lung Center will sponsor a 2-3 hour Saturday morning workshop and invite teen athletes, parents, coaches, and trainers. The marketing message will appeal to young athletes who desire to improve their athletic performance.

∞ ALA-I Lung Center Corporate Clinics. It is anticipated that senior level corporate managers will not go to a Lung Center. ALA-I will therefore actively pursue the corporate/professional market and take Lung Centers directly to the work-site.

8. ALA-I will conduct a market analysis to determine the efficacy of the various advertising vehicles.

A November evaluation of the ALA-I Lung Center in South Bend should provide an idea of what the future of Lung Centers in Indiana will be. Until then, local staff of the Lung Association and Memorial continue to press on diligently. What's the outlook for the Center? "I don't know," said Stephanie McCune, "I think once we get the doctors to learn this [the Lung Center] is an aid to them, then I think we'll make it." Dick Beall, after acknowledging the puzzle of trying to bring people in to the Lung Center says with determination, "We really and truly have to figure this thing out."

For more than a few patients, they already have. A mother who has visited the Center because of her toddler's asthma, says that at the Lung Center, "They have the time to sit down and explain everything – things you would never get from a doctor simply because they don't have the time. It was wonderful." She adds that both she and her husband have received information about their daughter's asthma through the Center that's helped them to understand and manage their child's disease.

A fifty-nine year old asthma sufferer first visited the Lung Center in December of 1998, and has returned for several information and instruction sessions since. Although she was able to hold a job before going to the Center, many every day activities, like carrying groceries or doing laundry, were things she couldn't do by herself. "I have come so far," she says, "In the beginning, you feel like you haven't accomplished a whole lot. It takes time. But then, you start feeling like, 'Oh, man, I'm doing something I haven't been able to do before. They're [Lung Center staff] really good. I have nothing but positive things to say about them. They are so many things I never thought about with asthma...It's marvelous to know. Last year, I couldn't even hold my grandchildren, because I couldn't pick them up," she says, "Now I can." Holding grandchildren, grocery shopping, walking, breathing -- simple things that really define what 'quality of life' is all about. Stories like these show best what the ALA-I Lung Center is truly working for.