

# CHOICES

THE CENTER FOR ETHICS AND ADVOCACY IN HEALTHCARE

Fall / Winter 2003

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*Sr. Peg McDonnell, Director*

Dear Friends,

At the start of another academic year, we want to share some of our recent adventures. Most importantly, the web site is finally up! Be sure to see Rachel's article on page four. Four interns joined us this summer and were of invaluable assistance with the day-to-day work. Of the six people working here, three had no health insurance, and two of these were high school students. I told them to write their stories as "case studies" and phone Springfield, Illinois so as to advocate on their own behalf. This they did, and they learned how to get their healthcare!

In May we had a wine reception for our donors to express our gratitude for contributing their time, money, and energy. Thanks to the generosity of local vendors, we were able to provide food and beverages as well as raffle prizes. We had over \$400 contributed by wonderful neighbors. As one person said, "You are clearly not alone!" and another, "The secret is out!"

At the reception I told some of our stories, which helped people understand what it is that The Center actually does. When we think and speak in terms of our belief in human dignity rather than on a specific task, it is understandably difficult to grasp exactly what it is that we do at The Center.

Though we find it hard to separate the work of ethics from advocacy, the expression of our work differs daily. For example, we are keenly aware of the difficulty people are having accessing care. Perhaps elderly and Medicaid recipients suffer most, but no one is exempt. In Illinois alone, 50% of the pharmacies can no longer sell prescription drugs to Medicaid recipients because these pharmacies are not reimbursed. So, in the work of advocacy we are building up our database of pharmacy resources. We also track healthcare-related political advocacy efforts and follow legal changes that impact the reimbursement system. News of cutbacks is so frequent and the news items are so often hidden that we are frequently caught by surprise. At the same time, we are learning that there are numerous ways to access less expensive care. The more information we can surface, the more helpful we can be to those who approach us.

In the work of ethics, issues around decisionmaking remain a constant challenge. For example, everyone cannot have everything, so how do we make decisions that are just? What about entitlement? Does the fact that someone has made a significant mark on society entitle them to more care? If others have lived a long and fulfilling life, should they not be entitled to as much care as a young person with a future?

Without the interns and part-time staff we would be lost. Without the support (of all kinds) that we have received from you, we would be lost. To quote John Haughey, SJ, founding board member, "When you embrace the vulnerable, you embrace God." We experience this on a day-to-day basis. May we continue!

Sincerely,

A handwritten signature in black ink that reads "M. Margaret McDonnell, RSCJ". The signature is written in a cursive style.

Peggy McDonnell, RSCJ

Director, The Center for Ethics and Advocacy in Healthcare

## WANTING TO DO JUSTICE IN HEALTHCARE

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## On the Inside, Looking Out-- Where Should End-of-Life Decisions be Made?

*The following essay was written by Lynn Cannon, a nurse who worked for 24 years in intensive care units in hospitals. She now works in the recovery room at Provena Mercy Center and teaches at Lewis University and Waubesa Community College. She holds a bachelor's degree in nursing from Marycrest College in Davenport, Iowa and a master's degree in nursing from Northern Illinois University. A resident of Naperville, she has two grown sons.*

I was working in the recovery room when a colleague from day surgery called to ask if I would help her get a patient ready for discharge. When I got to the bedside, I found our nurse, CS, visiting with the patient's wife. She explained as she asked the wife to step out that we needed to change the patient's diaper and get him dressed. She also said that even though the patient (I will call him John Doe) was cared for at home by his wife, she wanted to give her a rest for the short time that John was with us.

John was young, at least younger than I am, but, with a progressive neurological degenerative disease, he had been robbed of just about all movement and was completely dependent on someone for care.

I tried to avoid his eyes while we changed his wet diaper, but I could feel his eyes watching both of us. I wondered what he was thinking as these two strangers rolled him from side to side, pushing and shoving crinkling plastic diapers. Whatever it was, we could only guess, for the terrible disease toll included his speech, too. When we got to the point that I could finish by myself, CS went to finish discharge instructions with John's wife because the Medicare was scheduled to arrive soon.

CS and John's wife were still talking when they reentered his room. John's wife was saying that it was getting harder and harder to manage at home. This required their 19-year-old daughter to live at home and attend a nearby junior college so that she could also help with John's care. Other assistance came from their son, who was in high school.

John's wife said that she didn't know how John had managed to pull out the feeding tube again, but this was the second time that they had to transfer him to the hospital for re-

insertion. I thought to myself "where there is a will, there is a way," and I felt that perhaps we all needed to take a step back and look at this situation.

If this had been one of my inpatients during the years that I worked in intensive care, I would have proceeded to delve further into the story with both John and his wife. What exactly were their wishes and what decision-making capacity did John still have? I would have called the ethics consultant that very afternoon.

I doubt that pulling out the feeding tube was an accident. You understand that I have spent the majority of my nursing career on the inside, looking out --of the hospital, that is. Now I am frequently exposed to outpatients in both recovery room and in our sister unit, which is day surgery.

On the inside, there are processes and structures to assist us in everyday ethical decision making. But what is there "on the outside"? More and more of our healthcare is being delivered "on the outside." Thousands of patients like John and his family struggle without much support for making ethical decisions about life-sustaining treatment. Healthcare providers must understand the basic principles of ethics and how these apply to our patients wherever those patients are located. We need a place where more objective advice and expertise can be obtained.

First, families and caregivers need education; then end-of-life care-giving could be made within the community and family setting, not in the sterile and cold environment of some emergency room. Strong leadership is needed to get people talking and sharing some honest feelings about their beliefs and hopes.

—Lynn Cannon

## WANTING TO DO JUSTICE IN HEALTHCARE

### How The Center Can Help – A Response to Lynn Cannon

In her description of John's case, Lynn Cannon has identified a situation that would make an excellent referral to The Center. This referral is good because we must honor John's wishes and not assume he doesn't know because he cannot speak. Our process would make certain that we know what John wants.

In this particular situation we would need to determine: (1) Could we help? If so, (2) Where should the meeting take place—in the community or in the hospital? (3) Who should be involved? Family, practitioners, and, if at all possible, the patient should be involved. Patients "say" things by their actions, not only by their words. It is best if the patient could be there to indicate any desires. John might be trying to say, "I want to be allowed to die." He may want and need to be involved in order to indicate his wishes. Is he competent to take part in the decision, or is he too sick? This question would have to be answered.

In order for the conversation to take place in the hospital, permission must be appropriately obtained and the in-house ethics staff person should be involved. Outside of the hospital, possible conversation settings might include the home, the parish or synagogue, or a community center. A comfortable and safe setting is very important. I find that the home lends itself best to family gatherings like this. People need to feel "at home." Much of our work can be done by phone, but if it is necessary for staff, family, or practitioners to be present, then going to a conversation place (or vice versa) is best.

—Peggy McDonnell, RSCJ

### Website Information– [www.healthcare-ethics.org](http://www.healthcare-ethics.org)

- To read case studies on how The Center has played an effective role, please view our website. For reasons of confidentiality, we must be careful in the way we talk about our clients. Permission has been obtained for all published stories. As "tellable" stories become available we will put them on the website.
- A list of The Center's staff is posted on the website.

Gabriela started the internship along with everyone else, in the second week of June, 2003. She was with us one week, and

## INTERNSHIP 2003: ACTIONS SPRING FROM READINESS FOR RESPONSIBILITY

*During the internship program, the interns are exposed to issues around access to healthcare. How do we decide? What values should be safeguarded? At what level are decisions made? What about national healthcare priorities? How are individuals, families, and society being impacted? Personhood and human dignity? How do we balance individual rights with the common good? What is being done locally; how does The Center interface with other agencies? The students participated in field trips, guest lectures, and one - on - one conversations with those experiencing need. Students leave The Center with the knowledge to aid the public around the healthcare crisis, and often an excitement to pursue related careers.*

### The Center Gives Intern a New Experience

My name is Borim Yang. I am 19 years-old and I came from South Korea two and one-half years ago to study. I go to Regina Dominican High School in Wilmette and this fall enter my senior year.

I have a strong interest in a healthcare field, but, to tell the truth, my reason for becoming an intern is that I want to be part of something. For the past two years I wasn't involved in any extra activities besides school and church. I wanted to do something that I hadn't experienced before. I don't feel that I helped The Center because I took pre-calculus in summer school. I was at The Center for just two and one-half hours each day, but I learned from it. What I learned from my experience is that so many people need help to survive, but very few caregivers are available to help them. I learned how we can help people not by just talking, but by doing.

I know that as a community everyone should work together and help each other. Basically what I did was come to this internship to work with others and do the best I could. I think this is the point to be in any activities or communities.

—Borim Yang



Borim Yang

## INTERNSHIP 2003: ACTIONS SPRING FROM READINESS FOR RESPONSIBILITY

### Intern Helps Define The Center's Mission

During this internship, my main task was to organize and finalize The Center's website. We live in a world dominated by computers and technology, and I felt that the completion of the website would be essential for the growth of The Center and the spread of its message.

I believe that a not-for-profit organization cannot succeed without a clearly defined goal, so my first task was to understand what The Center does. I worked extensively with Sr. Peggy and other interns in order to understand the focus of The Center, and then to narrow the focus and better define The Center's work. Sister Peggy and I then created detailed website pages such as "About the Center" and "What the Center Does" in order to clarify The Center's goals and direction. I reviewed The Center's many case studies and chose those that I thought best reflected The Center's mission for the "Stories" page on the website. Our final edition of the website, which can be viewed at [www.healthcare-ethics.org](http://www.healthcare-ethics.org), was a collective effort on the part of all staff and interns, and I believe that it shows the clear and defined focus of The Center.



Rachel Adamczyk,  
Internship Supervisor

I also helped our high school interns clarify their research projects and attended many meetings of advocacy groups, including the National Center for Poverty Law and the Health and Medicine Policy Research Group. Both of these centers have links on our Internet Resources page. These field trips, along with the everyday discussions and presentations within our office, taught me a great deal about healthcare issues in America today.

My experience as an intern solidified my belief that we must find a way to aid or support those without healthcare benefits. In addition, the internship taught me about the experience of sickness and death. I have been fortunate in that I have never experienced the death of a close relative or friend. However, I have experienced feelings of frustration and helplessness when having a loved one in the hospital.

My experience at The Center, along with my personal experiences, affirmed my belief that people need support systems when dealing with illness or death, and when dealing with tough ethical issues surrounding death or extended care. I truly believe that The Center can provide those support systems. The Center acts as an intermediary between the frustrating world of hospitals, nursing homes, healthcare insurance companies and the concerns of patients and their families. I am proud to have been part of such an important organization, even if for a short while. I believe The Center will only grow and mature in these coming years, and I look forward to reading new stories of support and relief on The Center's Web site in the future.

—Rachel Adamczyk

### The Center Gave Intern a 'Jump Start' On Career

My name is Lann Choi and I am an 18-year-old Korean-American. I have just graduated from New Trier High School (Class of 2003) and will be attending the St. Louis College of Pharmacy this fall. I enjoy reading, traveling, volunteering, photography, and spending time with my friends and family. When I saw the posting at New Trier for an internship opportunity, and with my particular field of healthcare, I jumped at the chance.

Frankly, the words ethics and advocacy were not part of my everyday vocabulary. I had little or no relation, information or connection to these words. They seemed complex, with many meanings because so much of the language of ethics that we hear today has to do with big corporations and businessmen. How do we use these same words in the context of medical ethics? The words seem to have great power in the large industrial forces, yet they also are essential at the grass-roots level. In fact an overwhelming majority of the work that relates to these two words is hands-on, grass-roots work. How such a small center might be involved in the work and how important it is to The Center, were things I was going to find out.

The two words, ethics and advocacy, seemed so abstract to me. Before applying for the internship, I wanted to know what I was getting myself into, so I looked up the words in the dictionary. The word ethics means: *a system of moral standards*; advocacy: *the act of advocating, or speaking or writing in support*. With these definitions in mind I envisioned de-

## INTERNSHIP 2003: ACTIONS SPRING FROM READINESS FOR RESPONSIBILITY

*Continued From Page 4*

*standards; advocacy: the act of advocating, or speaking, or writing in support.* With these definitions in mind I envisioned debates, philosophical issues and conflicts. I've learned that these two words are more than philosophical debates and beliefs. There's a point of time in your life when instead of arguing your differing beliefs with a best friend, you must make a personal decision as to whether your beliefs will change someone's life, or yours. It's not abstract anymore. It's very concrete and real. Your decision is in front of you. There are effects and consequences based upon that decision. Rather than philosophical, the belief becomes physical. There's a decision to be made and action to be taken.

Knowing that the words would appear again in pharmacy, I looked forward to my internship. During my time at The Center I focused on issues in pharmacy ethics and advocacy. I compiled articles and researched websites on the controversial issues in pharmacy today. I have put many websites, articles, and papers together with information to assist the needy, uninsured, and those with low income. I also compiled updates on current Medicare issues.

By researching pharmacy-related issues, I have not only learned the many directions and opportunities in the field of pharmacy, but also the vastly different options in front of me. I will learn not only to dispense drugs, but also will be able to pick from a great range of research fields, including retail, legal, national, and international aspects of pharmacy.

As I complete this internship, I realize I have learned a great deal— a great deal about pharmacy, my community, and myself. I have a structured idea of the healthcare system today. There are many injustices, challenges, and obstacles we need to overcome. I have a jump start on what I will be facing as I start my career in pharmacy. As I have learned about many options in pharmacy, I have also learned that pharmacy, like many other careers, will involve ethics and advocacy. The Center has been a great contributor to my education and has prepared me for my future. There are no regrets about my decision to apply for this internship. With the knowledge and preparation I received at The Center, I feel confident and ready for my future. I approach my future and career with great ambition and hope.

—Lann Choi



Lann Choi

### Peacebuilders Initiative Inspires Intern

My name is Gabriela Lazcano. I am a 17-year-old Mexican-American. I live with my mother on the northwest side of Chicago. I start my senior year at Josephinum High School this fall. I am in the National Honor Society and am vice president of the Student Council. I also play volleyball. I took psychology for one semester and realized how much interest I have in the subject. I want to major in psychology when I go to college.

I was first interested in this internship because it would give me something to do and give me some job experience. I also was interested in the stories that Sister Peggy shared with us. It was only when I came here that I was really able to understand what The Center was all about. The Center gave me a sense of hope that uninformed, vulnerable people can be helped. Little by little, organizations such as this will help people realize that they do have choices.

When I got involved in another summer program, Peacebuilders Initiative, I learned that many homeless and elderly people suffer from different kinds of mental illness. I realized many things at Peacebuilders and, in a way, I am grateful that the program took place in the middle of my internship at The Center. Peacebuilders was a weeklong retreat that occurred during week two of my internship. There were 36 teenagers, ages 15 to 17. We shared a single purpose: to make a positive difference in our communities.

The Peacebuilders experience was unforgettable. It gave me a sense of hope and security to be with teens who believe in what I believe in, and are not afraid to show it. It was like living in a perfect pink-and-blue world for a whole week. Because we were kept away from televisions, radios, computers, and telephones, we were able to get in touch with ourselves and get in touch with God. I was surrounded by people my age who really wanted to be there. When we gathered in a room, I was able to feel immense happiness and energy. I feel that I have grown into a better person. I was reminded once again that there is a lot of power in prayer if one only has faith. I believe that it is essential for a person to believe in a power greater than one's self and, most importantly, to have faith in order to be able to manage and understand The Center's work.

When I returned to The Center for my third week, I enjoyed researching topics in psychology and learned many new things. Although I knew what I liked doing (learning about psychology), I could not see a connection between psychology

## INTERNSHIP 2003: ACTIONS SPRING FROM READINESS FOR RESPONSIBILITY

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and The Center. That was the hardest part of the internship. At times I felt useless, but someone was always there to help me. I learned not just from the tasks that I did, but also from the people I worked with. I discovered something new every day from each person.

My favorite speaker during the internship was Yvonne Hsiung. I really loved her presentation. Her topic was Chinese-Americans and how they make end-of life decisions. She explained many things about Chinese culture and why people behave in certain ways. For example, in China you do not wear a white collar when you visit a sick person because white represents death; you should not cry over a dead person because the person will feel the pain. The presentation made me realize how much my Hispanic culture has in common with other cultures.

Teenagers are not really known for spending their summer vacations doing community service or driving close to three hours every day just to get to work. But I was not the only one doing that. There were many like myself working hard because they wanted to make a difference. Of course I missed sleeping in and watching television all day, but God gave me a gift and it is my duty to share it with others. I wouldn't change last summer's experience for anything.

—Gabriela Lazcano



Gabriela Lazcano

### Interweaving Faith, Ethics and Community: A Reflection

Gabriela started the internship in the second week of June, 2003. She was with us one week, and then was out a week attending the retreat (see above). They had talks on theology, ministerial experiences, group prayer, and time for private prayer. They returned to their own homes the following Saturday.

When Gaby returned to The Center to continue her internship she was "in a different place." We all talked about it. It was clear that Gaby had a religious experience, or, better said, she had an experience of God that was so overpowering that she had a hard time "reentering" the internship program. When it came time for the interns to write an article for this newsletter as a way of "pulling this experience together" all Gaby could write about was her time at Peacebuilders. Obviously, I found this disconcerting! I kept telling Gaby to do more editing, try this, try that, but the article that Gaby wrote always came out the same: Peacebuilders was unique for her.

Two days before the internship ended I brought Gaby's article home and sat quietly with it. Suddenly I realized: Gaby really had had an experience of God, and coming back to "work" she experienced as, in a way, "losing" her retreat experience, though she had no words for this part of her experience. When I came to work the next morning I said to all of them: "Guess what? I think I have it!" I told them what I had realized: Gaby returned to work and suddenly she was in the struggle we all find ourselves in: Where is God in our every day? As soon as I said this the students all cheered in agreement. This resonated with their experience too, and with their experience walking with Gaby in these weeks.

The challenge continues: We must help them understand how faith, ethics and experiencing community come together. These three did finally come together that day in this small office where, with different cultures, religious backgrounds, ages and life experiences we named "the unnamable." Gaby's experience coupled with my insight gave our office community an understanding of what we all struggle with every day. Her difficulty integrating the two experiences became our difficulty, my insight became our insight, and in the process we were able to "name The Holy in our midst." This process is essential to preparing students for the world they are moving into. We must give them some understanding of how God "is" in their environment. They have to know that God is here and now and not "then and later."

What have I learned from this? I have learned that I must deeply *live* their struggles with them each day and I must be *discerning*. Because of our hard work at community building all summer, Gaby's spiritual experience became a spiritual experience for us all.

—Peggy McDonnell, RSCJ



Beth Shay and the 2003 Interns

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We take this opportunity to recognize and thank the following individuals who have generously donated funds to The Center for Ethics and Advocacy in Healthcare. We beg your indulgence for any oversight and would appreciate being notified of the same. Certainly, without this donor support, The Center would not be able to continue. Donor support gives meaning to the communal dimension of the work.

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*"Turn the crowd into a community-  
lift, hope, lead!"*

-From the soundtrack of the movie:  
*Roadsigns on a Merry-Go-Round*

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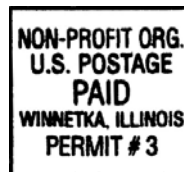
# CHOICES

THE CENTER FOR ETHICS AND  
ADVOCACY IN HEALTHCARE

2001 Waukegan Road

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## ABOUT THE CENTER: AN OVERVIEW

### VISION AND MISSION STATEMENT

“It is through the experience of others in situations of crisis, distress, vulnerability, weakness, and woundedness that the ultimate truth and meaning of every life is revealed.” (Michael Downey, *A Blessed Weakness*, Harper and Row, 1986)

#### VISION

The Center for Ethics and Advocacy in Health Care envisions a society that preserves and enhances personhood and human dignity in illness and dying.

#### MISSION

The Center for Ethics and Advocacy in Health Care, community-initiated and community-based, exists to help people make wise decisions as they move through our present healthcare institutions.

The Center effects a shift in decision making authority so that the individual becomes part of his or her own healthcare decisions. The Center works toward changing public policy in our country's healthcare system and supports the extension of this work into the community through its programs.

### IMPLEMENTATION

The Center for Ethics and Advocacy in Health Care's method starts with the person and his or her own individual story:

- ✓ Recognizing that each one has a unique story;
- ✓ Encouraging each person to give caregivers access to that story;
- ✓ Identifying and protecting the values in each person's life and decisions;
- ✓ Clarifying the moral conflicts inherent in life-and-death decisions;
- ✓ Gathering all pertinent information: personal, medical, social, psychological, and spiritual;
- ✓ Insuring that the patient, in concert with the family and caregiving community, makes the ultimate decision.

### EDUCATION TAKES PLACE

- ✓ Around the living room and dining room tables, that is, at the table of life;
- ✓ In the home, the marketplace, the classroom: wherever ethical and healthcare decisions are made;
- ✓ With the staff of hospitals, long-term care facilities, and other healthcare institutions;
- ✓ At ethics committee meetings involving patients' advocacy and the preservation of patients' rights;
- ✓ In the cracks between healthcare institutions and the community.