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Rondi L. Wightman

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The National Kidney Foundation of Illinois:

A Case of a Collaborative Effort in Transplant Education

Rondi L. Wightman

There are many opportunities for not-for-profit health care organizations to provide quality, transplant-focused education to renal patients, transplant candidates, transplant recipients, and health care providers.

In August 1998, I joined the National Kidney Foundation of Illinois (NKFI) after having worked for 8 years as a renal and pancreas transplant social worker in one of the most active transplant centers in Chicago.

Upon my arrival at the NKFI, my first professional and personal goal was to enhance the existing Patient Education Programs. Before 1998, the NKFI offered fewer than 3 patient programs per year. These programs focused primarily on the needs and issues of dialysis patients. Occasionally a transplant-specific topic would be included. With the input from a program planning committee, and my colleague Tina Haberer Weiss, who was at that time a 21-year kidney transplant recipient, I gradually introduced more renal transplant topics to the patient education days. The response was immediate and encouraging. Dialysis patients and their families began requesting more educational sessions on renal transplantation. Transplant recipients and their families were requesting educational programs that would help them better adjust to their new lifestyle.

There are 6 different transplant programs in Chicago offering kidney, pancreas, liver, small bowel, heart, and lung transplantation. Peoria, which is located in Central Illinois, offers heart and kidney transplantation, and Springfield, also located in

Central Illinois, offers kidney, pancreas, and heart transplantation.

The NKFI tried a variety of different approaches to patient education programs. One of our earlier efforts was a series of 3 "NKFI Kidney Classes" each focusing on a specific topic, Pre-End Stage Renal Disease, Dialysis as a Treatment Option, and Kidney Transplantation as a Treatment Option. An optional support group, lead by a licensed clinical social worker, was offered at the end of each session. Although the support meeting was optional, all program attendees remained and actively participated in these groups.

One of our first large-scale pediatric efforts resulted in an annual program called "Kids & Kidney Disease." This program is a direct result of professionals in the renal community requesting an educational program that would benefit children with kidney disease and their parents alike. Pediatric renal transplantation is the focus every other year. Kids & Kidney Disease is held at the Museum of Science and Industry and has 2 simultaneous programs, one for the children and one for their parents. Pediatric patients and their siblings enjoy a chaperoned "scavenger hunt for health" throughout the museum. The kids and their chaperones then enjoy an indoor "renal friendly" picnic lunch followed by fun and therapeutic activities designed by pediatric social workers, dietitians, and nurses.

At the same time, Kids & Kidney Disease offers parents, grandparents, and other family members the opportunity to hear lectures by some of the leading pediatric renal specialists. Parents and oth-

Rondi L. Wightman, M.S.W., L.C.S.W.,
C.A.D.C.

National Kidney Foundation of Illinois,
Inc.

215 West Illinois St., Suite 1C
Chicago, Illinois, USA 60610

Tel.: 312.321.1500

Fax: 312.321.1505

email: rondi_wightman@yahoo.com

er attendees then have a special opportunity to have more personal discussions with a variety of pediatric renal professionals during "Lunch with the Experts." Invitations are extended to all the pediatric programs and specialists to join the parents for lunch and informal discussions. Round tables of 10 are set up for lunch, with at least 2 pediatric professionals (physicians, nurses, dietitians, social workers) at each table.

"Giving the 'Gift of Life' Living Donor Reception" is an annual NKFI program designed to help increase awareness of the option for living organ donation. In its inception, this reception was to feature living kidney, liver, and lung donor and recipient pairs. These special donor and recipient pairs share their personal transplant experience in a panel presentation. The intended audience is transplant candidates, their friends, and family members.

After the panel presentation, audience and panel members have an opportunity to have more intimate conversations. Potential donors have the opportunity to talk with individuals who have already given the "Gift of Life." The emphasis of this evening is patient-to-patient interactions. However, a number of transplant surgeons, nurse coordinators, and social workers representing all local transplant centers attend and are available for attendees to speak with.

Although the NKFI has not yet created a scientific means to monitor which potential donor and recipient pairs that attend this reception eventually do make it to transplantation, it is our hope that by providing this unique opportunity many of these families will be encouraged, will consider, and eventually become living donors for their loved ones. The transplant surgeons in our community are encouraging the NKFI to host this reception twice per year.

The largest NKFI transplant-focused program is the annual "Living with Transplantation" event. This is a day-long educational program for pediatric and adult solid organ recipients of all organ types.

The keynote address is a general session, with all attendees together. The topic is selected to be of interest to all solid organ recipients. The morning break-out sessions are by transplant type. Sessions are offered for pediatric heart, lung, liver, pancreas, and kidney recipients and their family members.

Additional sessions are offered for adult kidney, heart, liver, and lung recipients and their family members. Two transplant professionals speak in each of these sessions, but on topics related to that specific organ transplant type. For example, during the adult kidney transplant session, one speaker might address the issue of re-transplantation and the other might address the topic of new immunosuppression.

Lunch with the Experts follows the morning break-out sessions. Invitations are extended to all the transplant programs to send up to 4 of their transplant professionals to sit at random tables for lunch (2 experts and 8 attendees). Lunch with the Experts provides an opportunity for more informal interactions between the transplant professionals and the program attendees.

Eight different topics are offered for the afternoon break-out sessions. Returning to Work and Social Security Benefits, Exercise and Wellness after Transplantation, How Transplant Impacts the Family (this session is an exclusive offering for family and friends of transplant recipients; transplant recipients are not allowed to attend), Stress Management and Relaxation Techniques, Living with Immunosuppression, and Understanding Medicare and Medicaid are just some examples.

The pediatric recipients enjoy their own age-appropriate program, while their parents and caregivers have a program designed just for them. Pediatric transplant professionals provide lectures on topics such as Pediatric Post Transplant Issues: Returning to School, Immunosuppressant Medications and Managing Their Side Effects, and Dental Issues in the Transplant Recipients.

Living with Transplantation drew 380 attendees this year. This program is a collaborative effort lead by the NKFI and involved a planning committee of 20 for the adult program and 9 for the pediatric programs. Members of the planning committee came from each of the transplant centers in Chicago, our local organ procurement organization, 3 patient-oriented groups, several not-for-profit health care organizations, and included a number of transplant recipients.

The NKFI has been described as a leader in providing innovative programs for patient education. Although the Patient Programs Department at the

NKFI works tirelessly on these monthly educational initiatives, we could not offer the quality programs we do without the ongoing support of our renal and transplant community. Physicians, surgeons, nurses, social workers, dietitians, and financial coordinators generously volunteer their time and expertise. Other not-for-profit health care organizations support our efforts by pooling resources,

sharing contacts, and helping us to promote these programs to their membership. Finally, the pharmaceutical industry has provided generous and much appreciated financial support to the NKFI. In so doing, the NKFI has kept the cost of these programs to patients minimal; and the program content, provided by some of the best professionals available, remains meaningful and comprehensive.