

2004-2005 Annual Report

LIFE OPTIONS

www.lifeoptions.org



*Dedicated to helping people live long
and live well with kidney disease.*



Introduction

As it has for the past 12 years, Life Options continues to provide unique, research-based resources to help people live long and well with kidney disease. Life Options highlights from 2004-2005 include:

- *In Control* was introduced in 2004 as a new supplement to *Nephrology News & Issues* magazine. This unique 2-in-1 newsletter pairs four pages of easy-to-use patient education information with four pages of professional education in each issue. A single topic that is important to people with chronic kidney disease is featured in each issue.
- The Life Options website was completely revised and updated in 2004. The new site features an easy-to-navigate home page, as well as a new, downloadable “Life Options Licensing Agreement,” which allows the user to print and distribute copies of any requested booklet. Site use tripled after the update.
- Life Options translated the popular *Keys to a Long Life* fact sheets into Spanish. The fact sheets are available to download as free PDF files from the Life Options website, and cover 12 topics ranging from Anemia, to Fluids, to Vascular Access.
- Life Options staff wrote and formatted 117, new patient education fact sheets based on topics from the Life Options *Keys to a Long Life* Patient Interest Checklists.
- A paper outlining findings from the ESRD Self-management Study appeared in the *Nephrology Nursing Journal* (Curtin RB, Sitter DC, Schatell D, Chewning BA. Self-management, knowledge, and functioning and well-being of patients on hemodialysis. *Nephrol Nurs J* 31(4):378-86, quiz 387, 2004.) Conducted with 372 randomly-selected patients, the study examined the relationships among education, self-management, and functioning and well-being (FWB), and suggested that effective patient self-management education is a key component of quality of life and survival for people with kidney disease.
- Life Options made Modules 1–15 of the popular Kidney School (www.kidneyschool.org), its interactive, online curriculum for people with kidney disease, available as free, downloadable PDF files.
- Online CE credits for Modules 1 & 2 of Kidney School™ became available to nurses and other professionals who are new to the field of dialysis. These modules now offer a convenient, economical way to earn CE credit while learning the basics about kidney disease.

In the end of our 12th year, we are proud of what Life Options has accomplished to date, and look forward to using the knowledge and insights gained from talking to thousands of people with kidney disease to help thousands of others in the years to come.

For More Information

Life Options is administered by the non-profit Medical Education Institute, Inc. of Madison, WI, and supported by Amgen Inc. Life Options’ free, research-based educational materials for patients and professionals are available from the award-winning Life Options website at www.lifeoptions.org. For more information, call the Life Options Rehabilitation Resource Center at (800) 468-7777, or e-mail lifeoptions@MEIresearch.org.

Contents

Research	2
Education & Communications	3
Liaison and Ripple Effect Activities	6
Kudos	8
In Closing	9
LORAC Members	9

Life Options initiated three new, groundbreaking studies in 2004:

Chronic Kidney Disease (CKD) Self-management Study

Can the link between self-management and improved physical and mental functioning found in people on dialysis also be identified earlier in kidney disease? A quantitative survey study to answer this question was fielded in partnership with Gambro Healthcare in Florida and the Medical College of Virginia. Subject recruitment was conducted at the University of Miami in Florida. The study explored relationships among participation in self-management activities, patient characteristics, selected lab test values, employment status, and health-related quality of life.

Data were analyzed and the resulting paper will be developed by Dr. Roberta Braun Curtin in 2006, and submitted for the consideration of the *American Journal of Kidney Diseases*.

Tailored Education for Dialysis Study

Research in other chronic diseases has shown that personalized patient education, tailored to individual interests and concerns, is more effective than “generalized” education efforts. To explore how a personalized education program might be put into use in busy dialysis clinics, Life Options designed and initiated its first intervention study in partnership with DaVita.

In 2004, IRB approval was obtained, and Life Options staff wrote and formatted 117, new 1- to 2-page patient education fact sheets based on topics from the Life Options *Keys to a Long Life* Patient Interest Checklists. A team of LORAC members reviewed all of the fact sheets. Topic areas for the 117 fact sheets included:

- Feelings (e.g., fatigue, depression, hopelessness)
- Relationships with family and friends
- Lifestyle and everyday activities
- Work/school/insurance
- Relationships with staff
- Diet and fluids

In 2005, the study was implemented, including staff training sessions and patient recruitment. Study group participants choose topics of interest and receive fact sheets on those topics, complete with action steps. By the end of 2005, 146 of the targeted 300 patients were recruited. Some of the initial clinics were sold, had staff turnover, or were victims of Hurricane Katrina, and have been replaced.

Life Options will examine dialysis patient knowledge, self-efficacy, and functioning and well-being before and after the intervention, compared to a control group receiving usual care. The fact sheets will be made available to the community via the Life Options website upon study completion.

Life Options Internet Study

Patient education can be offered efficiently and cost-effectively via the Internet, but patient educators in the field of chronic kidney disease are unsure whether dialysis patients can and do access web-based materials. Published statistics about the number of U.S. adults with Internet access suggest widespread—and increasing—numbers of people are online, but no data are currently available about dialysis patients.

In 2004, Life Options designed a research study to fill this information gap, developing a questionnaire about Internet access and patient education level. More than 1,800 in-center hemodialysis patients—both English-speaking and Spanish-speaking—from 37 centers around the United States completed the survey, and we completed data entry.

The resulting paper (authored by Dori Schatell, MS; Meg Wise, PhD; Kristi Klicko, CHES; and Bryan Becker, MD) will be submitted for the consideration of *American Journal of Kidney Diseases*. Findings were presented by Dori Schatell, MS at the 2005 ANNA meeting, the NKF of Illinois meeting, and the Annual Dialysis Conference in 2005.

Using research as its foundation, Life Options continued to provide practical tools to help patients live long and live well with kidney disease:

Life Options Website: www.lifeoptions.org

Now in its 12th year, the award-winning Life Options website continues to provide extensive, free resources to help people live long and live well with kidney disease, hosting an average of 18,000 visitors per month.

Completely revised and updated in 2004, the new site features an easy-to-navigate home page, where visitors can order or download free materials and find kidney disease information, patient stories, tips, and much more.

New features include a downloadable “Life Options Licensing Agreement.” This document—when completed, signed, and submitted to Life Options—allows the user to print and distribute copies of any requested booklet. The Agreement also allows users to “co-brand” the booklets by adding a name, address, and “this copy compliments of _____” in a 3-inch-square box on the lower front or back cover.

Other content of the new Life Options website includes:

- Downloadable free booklets, fact sheets, and manuals
- Order form for free videos, audiotapes, and posters
- Patient and professional stories & tips
- Extensive, annotated kidney links
- Moderated patient message boards
- A kidney glossary
- Symptoms, risk factors, and prevention of CKD
- A speaker's bureau

Materials requests continued to arrive via the online order form and toll-free number. In 2005, the RRC received more than 2,100 e-mail messages and phone calls from 37 states, and distributed more than 3,600 patient and professional materials, in addition to downloadable materials.

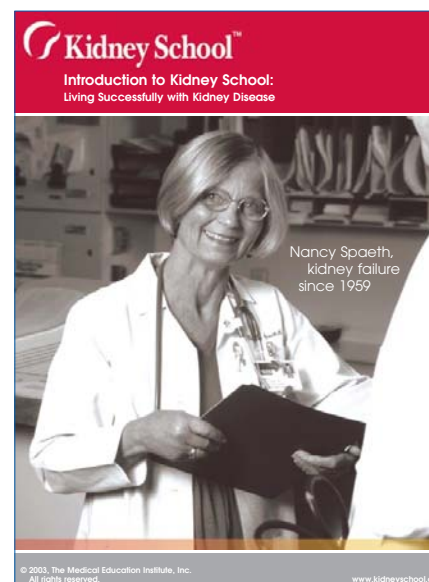
Kidney School™: www.kidneyschool.org

Launched in 2002, Kidney School is Life Options' interactive, web-based, tailored kidney learning center. We designed Kidney School to inspire, motivate, and empower people with kidney disease to take an active role in the self-management of their disease.

Each module contains lively content, a pre- and post-test, graphics and animations, patient quotes, photos, a user evaluation, and a certificate of completion. A Personal Action Plan can be printed for goal setting and review.

In 2005, more than 47,000 users visited Kidney School, and two new Modules were added: Module 14: *Patient Rights and Responsibilities* and Module 15: *Alternative Treatments*.

In addition, Kidney School content was made available to even more patients in a new way: the Kidney School curriculum was converted into PDF format suitable for downloading from the Internet, making it possible for patients and professionals to get print copies of Modules 1–15.



In 2004, Life Options obtained approval from the Wisconsin Nurses Association to offer continuing education (CE) credits to healthcare professionals for modules 1 and 2 of Kidney School. For a \$20 fee, entry-level nurses and patient care technicians can earn 2 hours of continuing education credit by completing the two modules. By the end of 2005, more than 40 people obtained CE credit by attending Kidney School online.

In Control

Published as a supplement to *Nephrology News & Issues* magazine, Life Options launched this unique 2-in-1 tool in March 2004. It's "2-in-1" because we pair four pages of easy-to-use patient education information with four pages of professional education in each issue. The patient education pages can be freely copied and can be used to supplement patient education in any clinical setting.

Each issue of *In Control* features a single topic that is important to people with chronic kidney disease. In 2004–2005, these focus topics were:

- Focus on Fistulas
- Linking CKD and Heart Disease
- Diabetes + Dialysis
- CKD and Job Retention
- Getting Enough Dialysis
- Herbal Products and CKD
- Managing Fatigue in CKD
- Preventing Conflict in Dialysis



Spanish Version of Keys to a Long Life Fact Sheets

In response to numerous community requests, Life Options translated the popular *Keys to a Long Life* fact sheets into Spanish. The fact sheets are available to download as free PDF files from the Life Options website at www.lifeoptions.org/catalog/catalog.php?prodCat=teachingTools.

The 2-page fact sheets are written at the 5th- to 6th-grade reading level and are translated into "Spanish for the U.S."—a translation that avoids all local nuances and regional vocabulary, creating a standard text that allows for easy comprehension for all Spanish speakers. The fact sheets cover 12 topics:

1. Anemia
2. Depression
3. The Dialysis Machine
4. Exercise
5. Fluids
6. Hemodialysis Adequacy
7. How to Talk to Your Healthcare Team
8. Rehabilitation
9. Restless Legs Syndrome
10. Skin and Hair Problems on Dialysis
11. Traveling on Dialysis
12. Vascular Access

In addition to the easy-to-read and substantive content, the sheets feature resources (when available in Spanish) and frequently-asked questions. Copyright has been released so staff may freely copy and distribute the fact sheets. A panel of Life Options Rehabilitation Advisory Council (LORAC) members reviewed the material prior to publication. Ramiro Valdez, PhD, Director of Patient Services for ESRD Network of Texas, served as a special reviewer on this project, verifying translation.

Journal Articles, Abstracts, Presentations, Exhibits, and Press Releases

In 2004–2005, Life Options initiatives were featured nationally in a variety of journal articles, abstracts, presentations, exhibits, and press releases:

Journal Articles and Abstracts

- Curtin RB, Sitter DC, Schatell D, Chewning BA. Self-management, knowledge, and functioning and well-being of patients on hemodialysis. *Nephrol Nurs J* 31(4):378-86, quiz 387, 2004

- Witten B, Schatell DR, Becker BN. Relationship of ESRD working-age patient employment to treatment modality. *J Am Soc Nephrol* 15:633A, 2004
- Witten B. Living well through school, paid, or volunteer work. *Family Focus*, Spring 2004
- Witten B, Schatell D. Anemia: Dialysis patients' experiences. *Nephrol News Issues* 18(12):49-54, 2004(6): 1286-1292, 2003
- Schatell D. Renal resources online. *Nephrol News Issues* 18(12):55, 2004
- Schatell D, Witten B. Dialysis patient empowerment: What, why, and how. *Nephrol News Issues* 19(9):37-39, 44, 2005
- Curtin RB, Mapes D, Schatell D, Burrows-Hudson S. Self-management in ESRD: Exploring its domains and dimensions. *Nephrol Nurs J* 32(4):389-395, 2005

Presentations

- *Avoiding Hyperparathyroidism: Psychosocial Considerations*, Amgen marketing meeting, February 2004, delivered by Beth Witten in St. Louis, MO
- Renal Professionals' Reactions to Life Options Kidney School™. Poster presented at the Forum of ESRD Networks Annual Meeting, March 22-24, 2004
- *Patient Education Via the Internet*, NKF of Illinois Dialysis in the 21st Century meeting, September 2004, delivered by Dori Schatell in Chicago, IL
- *The Human Cost of Cost Containment: Patients' Lived Experience of Anemia*, National Renal Administrators Association meeting, September 2004, delivered by Dori Schatell in Denver, CO
- *Kidney School: A Versatile Patient Education Resource*, ESRD Network 13 professional meetings, October 2004, delivered three times by Dori Schatell in New Orleans, Little Rock, and Oklahoma City
- *Kidney School: A Versatile Patient Education Resource*, ESRD Network 14 professional meeting, October 2004, delivered by Dori Schatell in Dallas, TX
- *Relationship of ESRD Working-age Patient Employment to Treatment Modality*. Poster presented at the ASN Meeting, St. Louis, MO, October 31, 2004
- *The Human Cost of Cost Containment: Patients' Lived Experience of Anemia*, Amgen sales force meeting, December 2004, delivered by Dori Schatell in Orlando, FL
- *Kidney School: A Chronic Kidney Disease Patient Education Program*, Annual Dialysis Conference, February 2005, delivered by Dori Schatell in Tampa, FL
- *Kidney School™: A Kidney Disease Patient Education Program*, Wisconsin Dialysis staff in-service, March 2005, delivered by Eva Duran in Madison, WI
- *The Role of Anemia in Patient Self-management*, California Dialysis Council Meeting, April 2005, delivered by Dori Schatell in Palm Springs, CA
- *The Patient Perspective on Anemia*, ANNA Annual Meeting, Amgen Breakfast Symposium, April 2005, delivered by Dori Schatell in Las Vegas, NV
- *Partnering with Patients through the Internet: Creative Ways to Teach Patients*, ANNA Annual Meeting, April 2005, delivered by Dori Schatell in Las Vegas, NV
- *ESRD Patient Education via the Internet*, NKF of Michigan, September 2005, delivered by Dori Schatell in Marquette, MI
- *How to Help Kidney Patients Live Long and Live Well*, NKF of Tennessee, September 2005, delivered by Dori Schatell in Nashville, TN
- *ESRD Patient Education via the Internet*, NKF of Wisconsin, September 2005, delivered by Dori Schatell in Madison, WI
- *Nephrology Social Work Self-Advocacy in the 21st Century*, NKF of Georgia, September 2005, delivered by Beth Witten in Ponte Vedra Beach, FL
- *How to Help Kidney Patients Live Long and Live Well: Lessons from Life Options*, Northwest Kidney Centers social workers, October 2005, delivered by Dori Schatell in Seattle, WA

Exhibits

In 2004-2005, Life Options increased its visibility in the renal community by exhibiting at several national meetings, including:

- Renal Support Network, Denver, CO, September 2004
- NRAA, Denver, CO, September 2004
- National Kidney Foundation of WI, Madison, WI, August 2004
- Network 13 professionals, Oklahoma City, OK, October 2004
- Network 13 professionals, New Orleans, LA, October 2004
- Network 14 professionals, Dallas, TX, October 2004
- Kidney Disease Economics Conference, Phoenix, AZ, February 2005
- 25th Annual Dialysis Conference, Tampa, FL, February-March 2005
- ANNA 36th National Symposium, Las Vegas, NV, April 2005
- 32nd Annual AAKP Convention, Las Vegas, NV, September 2005
- Northwest Kidney Centers, Family Health and Kidney Expo, Seattle, WA, October 2005
- ASN 38th Annual Meeting & Scientific Exposition, Philadelphia, PA, November 2005



Press Releases

In 2004-2005, Life Options announced major program developments in the following news releases, which combined to reach more than 3,600 media and kidney community contacts:

- Free Print Versions of Life Options Kidney School Modules Now Available for Download
- Patient Rights and Responsibilities Module of Life Options Kidney School Now On-line
- By Popular Demand! Continuing Education Credits for Nurses Available for Kidney School Modules
- New PDF Versions of Life Options Kidney School Modules 1-8 and CE Credits Now Available
- Popular Nutrition Module of Life Options Kidney School Now Available to Download
- New PDF Versions of Life Options Kidney School Modules 10-12
- Alternative Treatments Module of Life Options Kidney School Now On-line
- Medical Education Institute Updates Popular Life Options Website
- Medical Education Institute Websites Meet Health On the Net Code of Conduct Standards
- Free Spanish Versions of Life Options Fact Sheets Now Available for Download
- Roberta Braun Curtin, PhD, RN Wins Nephrology Nursing Journal Award
- New PDF Versions of Life Options Kidney School Modules 13-15

Liaison & Ripple Effect Activities

As an active member of the renal community, Life Options continues to form partnerships with dialysis providers, ESRD Networks, and other organizations, primarily through their contact with the Life Options Resource Center. Key Life Options liaison activities in 2004-2005 included:

Sample Legislative and Other Governmental Activities

- Promoted FWB assessment, patient education, home dialysis in Kidney Care Partners Board and Workgroup meetings
- Reviewed and offered suggestions on letters Kidney Care Partners sent to CMS
- Communicated with CMS regarding psychosocial issues to consider in daily dialysis research
- Served as a member of the National Kidney Disease Education Program (NKDEP) Patient At-risk Workgroup
- Served as a member of the National Kidney and Urologic Disease Information Clearinghouse Coordinating Panel

- Developed and circulated to LORAC members rehabilitation-related comments for the Proposed Rule Change to the *Conditions for Coverage for End-Stage Renal Disease Facilities* (published in the Federal Register on 2/4/05); the change features several references to Life Options, including:
 - Use of the Life Options definition of rehabilitation
 - Citation of the Life Options white paper, *Bridging the Barriers*
 - Agreement with the Life Options assessment of the value of rehabilitation
- Provided leadership for the Beneficiary Education work group for CMS' Fistula First breakthrough initiative, facilitating work group meetings and reporting.
- Communicated with Allen Jensen, policy writer, about continuation of Medicaid under 1619(b)
- Talked with CMS about ways to help Katrina evacuees
- Suggested resources on emergency preparedness for CDC

Sample Community Activities

- Provided patient input on EPO HMA policy change
- Served on the Editorial Board for the NKF publication *CKD Update*; recommended speakers for issues on rehabilitation and wrote articles on employment
- Fulfilled multiple community requests for abstracts and articles on various topics, including anemia and functioning
- Helped AKF design program to help patients get Renagel®
- Reviewed NKF booklet on working with kidney disease
- Reviewed compendium for National Kidney Disease Education Program
- Advocated for NKF to support a special enrollment period for ESRD patients to sign up for Part B without penalty
- Reviewed and revised COBRA fact sheet for CNSW
- Reviewed and made suggestions on Renal Care Group fact sheet of websites for patients
- Helped with planning and implementing Kidney Disease Economics Conference
- Helped collect data for report on daily dialysis for Aksys
- Revised *Family Focus* article
- Advocated with legislators for HRSA funding for living organ donors
- Reviewed and edited paper for *Advances in Chronic Kidney Disease*
- Helped to locate authors for *Advances in Chronic Kidney Disease*
- Assisted NKF in designing program to assist people with home modifications for home dialysis
- Recommended people for NKF's patient advocacy organization
- Advised NKF that as designed, the 7 month enrollment period for Part B unduly limits time to apply for people with transplants and on home dialysis

Sample ESRD Network Activities

- Served on the Patient Safety Advisory Committee of ESRD Network of New England
- Worked with Mid-Atlantic Renal Coalition to help them revise their diabetes self-management education brochure
- Provided employment and work incentive information to Network 7 for their newsletter
- Helped Network 8 with query about legality of charging an administrative fee for transient dialysis
- Made rehabilitation recommendations for the ESRD Network Statement of Work public comment period
- Collaborated with Networks to resolve patient conflicts
- Coordinated with the Director of IS for ESRD Network 4 to copy and distribute 300 CDs of *Employment: A Kidney Patient's Guide to Working and Paying for Treatment* to dialysis and transplant units within PA and DE
- Reviewed and submitted comments on the new ESRD Networks' Scope of Work, aimed at refocusing the Networks' efforts on rehabilitation and employment—as per the original legislative intent

Kudos

“I have two cases of videos for my patients and am so very grateful for these. Thank you very much. I really believe your Kidney School and Life Options materials are the best out there. I have a goal of printing up all the Kidney School masters on double-sided paper and start a library for all staff to educate.... I give everyone your cards too.” —L.W., nurse

“So glad to have your wonderful materials—in fact, have a blind patient who listens to tapes and loves them. They motivate her.” —H.C., dietitian

“I just had to write to you to tell you that I got on the kidneyschool.org website and actually took one of the pre-module tests,” reported Linda. **“This was fascinating to me since I have never had an interactive experience like this on a website. Also, it was very blind-friendly, much better than many websites that I have been on. I couldn’t believe how, when I picked one of the multiple choices, my speech reader would automatically read the question to me with my answer inserted. And then told me how many I had correct!”** —L.S., patient

“I teach about renal problems and I am recommending this site to my students for review and to be able to teach and recommend to their patients.” —Instructor (re: Kidney School)

“Thank you for your educational information. It is very reassuring to find such positive literature/materials on ESRD. Thank you.” —M.J.L., patient

“Your materials are invaluable—thank you for educating the public.” —Patient

“I would like to thank you for your wonderful website. It is a very valuable resource and I do appreciate all the time and effort that must have gone into developing such a powerful and uplifting tool.” —H., patient

“I thought you’d want to hear the good news: my reluctant patient finally agreed to sign up for Medicare...thanks for your help and advice! I think we avoided some serious monetary woes here.” —J.V., social worker

“Thanks Beth for sharing your words of wisdom and experience.... It is helpful to me to learn as much as I can. I really am feeling heaps better. And starting to get used to a bit more exercise. The risks of not looking after myself this way are pretty scary but I think I’m getting on the right track. Thanks for your support. It makes a difference.” —Posted on Life Options message board

“I do feel bad about my condition sometimes but this site [Kidney School] had made me realize once more that things could be worse and there are other people out there with the same problem as me and could help me understand it better and no longer feel bad.” —17-year-old girl with transplant

“Thank you for having all the information you have because I thought that there was no one that understood what I am going through. You have given me something good to look forward to and not to see this as a negative way of living.” —Patient (re: Kidney School)

“Kidney School takes some of the fear and confusion away and makes life a lot less stressful.” —Patient

“I wish that this module had been part of my training for PD—the action plan is really a wonderful tool for facing the realities of what a new dialysis patient needs to deal with.” —Patient (re: Kidney School)

“I truly enjoyed your [Kidney School]. The information was and is very helpful to me in monitoring my husband’s conditions in the hospital and having to deal with the medical doctors. I recommend that everyone should learn your system. Your information gave me knowledge which in turn gave power. Peace and blessings.” —Wife of patient

“I want to learn as much as I can to help my child live as long as he can without fear from this. I don’t want to fear of him dieing [sic] again.” —Mother of 9-year-old with kidney disease

“This is a MAGNIFICENT, INFORMATIVE, WELL-WRITTEN, and FUN website. It is by the grace of god that I stumbled onto it. You are able to project such a PERSONAL feel and PERSONAL involvement. THANK YOU!” —Anonymous (re: Kidney School)

“I wish I had heard about this course [Kidney School] when my husband was first diagnosed 3 years ago. It’s been trial and error learning for us. This would have been so helpful.” —Anonymous

“I am a medical professional, but still found the info helpful. Thank you.” —Family member (re: Kidney School)

In Closing

With support from Amgen Inc. and continued cooperation and encouragement from the renal community, Life Options has reached and impacted countless numbers of kidney patients and professionals. Thank you to all who have supported our efforts!

LORAC Members

Life Options greatly appreciates the review time and expertise contributed by current and emeritus LORAC members (listed below) in 2004-2005:

Council Members

Bryan Becker, MD, FACP, LORAC Chair

Madison, Wisconsin

Sally Burrows-Hudson, MSN, RN, CNN

Sunnyvale, California

Mary Beth Callahan, ACSW/LMSW-ACP

Dallas, Texas

Jerry Fuller, MSW, LCSW

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