

D. IMPROVE COLLABORATION WITH PROVIDERS TO ENSURE ACHIEVEMENT OF THE GOALS THROUGH THE MOST EFFICIENT AND EFFECTIVE MEANS POSSIBLE, WITH RECOGNITION OF THE DIFFERENCES AMONG PROVIDERS (E.G., INDEPENDENT, HOSPITAL-BASED, MEMBER OF A GROUP, AFFILIATE OF AN ORGANIZATION, ETC.) AND THE ASSOCIATED POSSIBILITIES/CAPABILITIES

➤ **20th Annual Network of New England Educational Meeting**

The Annual Meeting “Moving Forward by Looking Back – How We Got Here and Where We Are Going” was held in Sturbridge, MA on October 16th 2008. The topics were:

- Historical Reflections of the Network Program
- ESRD in New England: Issues and Challenges in the care of patients on Dialysis
- Rapid Cycle Improvement: Simple Methods, Powerful Results
- Altered Metabolism in Advanced Chronic Kidney Failure: How It Affects Nutrition in Dialysis Patients
- Nutritional Management of the Maintenance Dialysis Patient: So What Do We Do Now?
- Vascular Access: Historical Perspective on More than 60 Years of Hemodialysis Access
- The Native AVF – Today and Into the Future
- Fistula First – Catheter Last
- There and Back Again: Relearning Infection Control
- Depression in CKD Patients: Learning from the Past and Moving Forward
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With a total of 600 participants, the attendees included nurses, dietitians, social workers, technicians, patients, physicians, surveyors, and other healthcare personnel including 80 exhibitors. There were 2 special exhibits and posters submitted from a variety of professional ESRD disciplines. Poster topics included:

- ARA – Springfield Dialysis Center “Peritoneal Dialysis Program Achieves Pursuit of Excellence”
- Caritas St. Elizabeth’s Medical Center of Boston “Fistula First Educational Program”
- Fletcher Allen Healthcare – Vermont “Vein Preservation for Chronic Kidney Disease Patients”
- FMC Mashpee/Cape Cod Artificial Kidney Center “The Challenges of Maintaining Phosphorus and Albumin Goals”
- FMC – NA Damariscotta Dialysis “Take a Bite, Take a Binder”
- FMC Plymouth “Picture This”
- Fresenius Medical Care of Warwick “Benefits of Tandem Dialysis”
- Goddard Brockton Kidney Center “Successful Return to PD Following Surgical Pleurodesis for Hydrothorax”
- Massachusetts General Hospital “Plasmapheresis In the Hemodialysis Setting”

- New Haven Home Dialysis “Peritonitis in Patients > 75 Years: A 20 Year Retrospective Study”, “Seasonal Variations in Peritonitis Rates”, “Compliance Among Home CPD Patients: Tell The Truth”, “Dialysis Withdrawal in a Large Peritoneal Dialysis Population”, “Factors Affecting Chronic Peritoneal Dialysis (CPD) Dropout”
- Western Mass Kidney Center “A Novel, Team Approach to Reducing Hemodialysis Catheter Related Infections”

➤ **New Conditions for Coverage Meeting**

This Network, at the request of dialysis providers, hosted a technical assistance meeting on November 13th 2008 in Sturbridge, MA. There were approximately 130 attendees. The program included a speaker from CMS Boston Regional Office, President of the Renal Physicians Association and Network staff. Attendees were asked to submit written questions that could not be addressed which were sent to CMS Central Office. The responses have been posted to the Network website.

- “Welcome and Overview of Conditions for Coverage”
- “Role of Medical Director and Leadership”
- “What is Quality Assessment and Performance Improvement (QAPI)”
- “Patient Assessment, Care Plan and Rights”
- “Facility and Patient Safety”
- “Sharing Ideas, resources, Suggestions for Next Steps”

➤ **Dialysis Technician Educational Meeting**

On April 24th 2008, Network #1 hosted an educational day for only technicians in Sturbridge, MA. The purpose of this meeting was to discuss clinical issues related to the care of ESRD patients, practical approaches to help renal patients achieve the best quality of life. The program was approved for 5.4 contact hours through NANT (National Association of Nephrology Technicians/Technologists). A total of 260 technicians attended the meeting. Topics discussed were:

- “Clinical Performance in the Network of New England: How Are We Doing?”
- “Patient Safety and Medical Mistakes: Where Are We in ESRD?”
- “Big Bad Bugs in the Dialysis Unit: Staph, MRSA, VRE – Prevention and Treatment?”
- “Transplant Candidacy: Is Social Equity, Clinical Utility, and Human Justice Possible?”
- “Your Work Team – Assess and Excel”
- “Keep It Real: Being Personable and Professional as a Patient Care Technician”
- “Be Your Patients’ Cannulation Idol”

➤ **Network Notes Published in 2008**

In July, 2008 the ESRD Network of New England issued its Summer (Special) issue of Network Notes; our traditional newsletter for New England renal professionals. The publication is sent to alert, inform, clarify and educate renal caregivers about current events, updates on Medicare rules, and other topics of relevance. In this issue a four-page insert was included with information about

the impact of the new CMS ESRD Conditions for Coverage specifically on Social Workers. The new CfC will become effective 10/14/2008. Other articles in the Summer edition were; Fistula First update, Information and preparation tips for the CROWN web change over, re-announcement of the usefulness of the Decreasing Dialysis Patient Provider Conflict (DPC) Toolkit and information to providers about how to participate in the Five Diamonds patient safety program. Network Notes is distributed to New England Renal Nurses, Medical Directors, Facility Administrators, Social Workers, and state surveyors.

In December, 2008 the ESRD Network of New England published and distributed the Winter Issue/Holiday Greeting of Network Notes, a newsletter which contains information targeted toward New England professionals. In the 2008-2009 Winter Issue, four articles were provided on the topics of Conditions for Coverage for ESRD providers under CMS, tips for preparing for the new Network-wide data entry system; CrownWeb, an update on New England progress as directed by the CMS Fistula first quality improvement project and an update on the Five Diamond patient Safety Program. A traditional feature of the winter Issue of Network Notes – the newsletter also carried a Holiday greeting from the Network staff to all ESRD partners in the six New England states who receive the publication.

➤ **Emergency Preparedness**

Chronic kidney failure, or ESRD, is a life threatening condition affecting nearly 12,000 patients (hemodialysis and peritoneal dialysis) in the New England region in 2008, all of which necessitate unique emergency needs in the event of a major disaster. ESRD patients require either medications to prevent rejection of a transplanted kidney, or regular kidney dialysis treatments to clean their blood of toxins as frequently as three to four times a week. Missing even a few dialysis treatments (2-3 days) can result in severe complications or even death.

The availability of community resources will vary depending on the type emergency encountered, and must be considered in any disaster planning. Subsequent to past national disasters, dialysis facilities, transplant centers, patients and professional organizations, and other strategic partners involved in kidney disease recognized the need to improve planning and preparedness for major emergencies. As a result of this need, the Network of New England developed an emergency and pandemic work plan to ensure emergency operations support and coordination of activities in the event of a disaster, and to assist ESRD facilities in the Network #1 area in the development or improvement of its provider-specific emergency preparedness plan for its facility and patients.

▪ ***Network Business Continuity and Contingency Plan***

Network of New England maintains a Business Continuity and Contingency Plan (BCCP) document, as required by CMS. This document lists roles and responsibilities for staff at times of emergencies to the Network of New England's physical site and information technology infrastructure. It also states the name of the back-up Network Organization that assumes responsibilities when, and if, the staff at Network of New England are unable to perform its duties. The BCCP is annually reviewed, updated and shared with Network staff. As required by the contract, the BCCP is submitted to CMS Project Officer.

- ***Kidney Community Emergency Response (KCER) Coalition***

In January 2006, CMS coordinated a National Disaster Summit to develop and coordinate disaster response in the ESRD community, to plan for the future, and to initiate the formation of a national coalition, “Kidney Community Emergency Response Coalition” (KCER) www.KCERcoalition.com. KCER is comprised of representatives from the renal community (patient and professional organizations, practitioners, ESRD Network Organizations, large dialysis organizations, independent dialysis and transplant facilities, suppliers, and state survey and certification and emergency representatives, as well as CMS, FDA, CDC, and other Federal agencies), and an administrative core group from Network # 7. Eight workgroups have been developed to work on individual parts of the overall plan (Patient Assistance, Communication, Facility and Patient Tracking, Federal Response, Facility Operations and Industry Supplies and Services, Coordination of Staff and Volunteers, Physician Placement and Assistance, and Pandemic Preparedness). Network of New England Staff serve on three of the eight response teams, participating in periodic conference calls, development of resource tools, mock drills and disaster assistance.

- ***Partnerships with State Agencies***

In the summer of 2008, the Network of New England collaborated with the Connecticut Department of Public Health to coordinate a statewide conference on Continuity of Operations Planning (COOP) pertaining to influenza pandemic and how vulnerable populations will be impacted. The conference, hosted on September 25, 2008, educated Connecticut medical professionals - nursing homes, home care clinics and dialysis providers - about state plans and regulation waivers in the event of a pandemic, provide infection control recommendations, and useful checklists/tools for patients and staff. There were over 300 in attendance, of which 25 were dialysis staff. A special breakout session, specific to the dialysis community, took place in the afternoon. Guest speaker, Wendy Fung-Schrag, Director of Advocacy and Governmental Affairs, FMC North America, discussed KCER (Kidney Community Emergency Response coalition) services with regards to pandemic preparedness and response.

- **Donate Life Connecticut**

Donate Life Connecticut (DLC) is a statewide coalition of volunteer agencies and individuals with shared interest in public education about organ and tissue donation, and increasing the number of transplanted organs and tissues, which give new life and hope to people suffering from a fatal illness or life threatening injury. This coalition is a non-profit corporation, with a 501(c)(3) tax exempt status. Activities are coordinated by a part-time Project Manager, with volunteers and agency members contributing time and in-kind resources. The Board of Directors meets quarterly via face-to-face or by conference call. Monthly membership meetings are held at the Connecticut Hospital Association. An Annual Meeting is held in June. The Network Executive Director serving as an officer on the Board of Directors in the capacity of Treasurer, while the Network Community Development Coordinator serving as a Board alternate.

In 2008 several activities and projects were successfully completed and participated by Network of New England staff through its collaboration with Donate Life Connecticut, including:

- Collaboration with the African American Affairs Commission for minority donor awareness
- 19th Annual High School Poster Contest
- Participated in the national Tree of Life campaign
- National Donate Life Month Celebration at CT State Capitol
- Thanks for Asking / Caring Campaign
- Secured \$115,000 in grant funding
- College outreach program through Students for Organ Donation (SOD)
- Registered organizations and corporations for Workplace Partnership for Life
- Increased membership by from 14 members in 2007 to 29 members in 2008
- Launched statewide media campaign during National Donate Life Month
- Supported the Team CT at U.S. Transplant Games
- Created a Facebook page for greater outreach to help the public

**State of Connecticut
2008 Donor Designation Rate**

Month	# of Registered Organ Donors (Licensed Drivers & ID Holders)
January	934,173
February	937,938
March	940,400
April	944,094
May	946,612
June	949,009
July	952,293
August	955,092
September	958,450
October	959,999
November	960,826
December	964,973

➤ **Donor Designation Collaborative**

The Network #1 Community Development Coordinator continues to serve as a representative of Network of New England, by participating in the National Donate Life America's Donor Designation Collaborative to help increase the number of actionable donor designations in New England. The focus of this collaborative effort is built on the successful use of the "Model for Improvement". The Donor Designation Collaborative is designed to assist regional and state-based teams in founding (establishing), fixing (improving), or filling (promoting) donor registries and tracking progress towards state and national donor designation goals. The Donor Designation Collaborative identifies and spreads best practices in the areas of measurement and analysis; effective partnerships and relationships; registry development, management and promotion; and to apply proven methods for organizational change and improvement. Through local monthly meetings and activities, and various local and national conference calls, the New England team has planned, designed, tested, implemented and measured changes in its respective states.

➤ **The Patient Advisory Committee “PAC” Matures Into a Strong Member of the Network #1 Team**

The New England Patient Advisory committee (PAC), a standing committee of the board of Directors, marked its ten year anniversary in 2008. As the name implies, the PAC serves as advisory on matters of interest to dialysis patients in consultation with the BOD, MRB and Network staff. The PAC is comprised of members from the six New England states representing patients, caregivers and balanced by treatment modality types (PD, Hemodialysis and transplant), gender, age and cultural background.

In 2008, as its most ambitious undertaking, the PAC completely revised the longstanding patient education publication entitled; *Your New Life*. The PAC unveiled and distributed more than 500 copies of the new edition of the thirty-six (36) page booklet at the Annual Meeting held in Sturbridge, MA, accompanied by an order form to request more copies of the free publication. ESRD professionals attending the meeting were instructed to use the order forms to FAX requests into the Network office in order to receive larger quantities of the publication for distribution to their patients. These booklets and other locally developed educational materials are made available to New England patients and family members – at no cost – by this ESRD Network.

Your New Life was first produced more than twenty years ago and provided to New England ESRD patients and family members when they began dialysis treatments for renal failure. The first version of the booklet was developed by Network staff, but has since become primarily authored by the PAC, with staff and Board editing. *Your New Life* is designed to provide information, orientation, education and reassurance to patients facing new life challenges. The booklet has printed text, information and graphics on the topics of; hemodialysis, peritoneal dialysis, transplantation, emotional adjustment, financial issues, nutritional needs, exercise and aspects of intimacy. The *Your New Life* booklet is considered a centerpiece of patient education/orientation for New England dialysis patients by ESRD providers throughout the six states served by this Network. The PAC is proud to author this well recognized and respected educational product. In turn the Network is proud of its PAC.

➤ **5 Diamond Patient Safety Project**

This patient safety project was a joint collaborative effort between Network #5 and this Network. It was launched in New England at the Technician Education Program in April 2008. The purpose of this project is to provide fully developed staff educational modules on eight different topics. The first topic is the principles of safety, a required module for all providers enrolled in this project. The other modules are:

- Hand Washing (Infection Control)
- Influenza Vaccination
- Slips, Trips and Falls
- Emergency Preparedness
- Sharps Safety
- Decreasing Dialysis Patient Provider Conflict
- Medication Reconciliation

This project has been endorsed by ANNA and the RPA. As of December 2008, there were 26 providers registered in this program of which 7 providers successfully completed 5 modules and were awarded 5 Diamond plaques.

➤ **Forum of ESRD Networks**

Network #1 Executive Director and the Network #1 past chair currently serve on the Forum Board of Directors. During 2008, the Forum as a voting member of the National Quality Forum has commented and voted on clinical measures of importance to ESRD patients. This organization is also a member of the Kidney Care Quality Alliance. The Forum has communicated with CMS/QCSQ leadership on topics related to Networks such as Network redesign and attribution.

➤ **State Survey Agencies**

Network #1 maintains a registry of state ESRD surveyors in all six New England states. Each year routine material on ESRD data and Network #1 activities is shared with each surveyor. Consultation and information sharing on provider performance and policy issues are provided as requested. More frequent calls from state surveyors seeking background information on procedures is taking place. In May 2008, the Network Executive Director was invited by the Massachusetts Department of Health to give a presentation on ESRD to all surveyors. Approximately 25 people attended.

➤ **Quality Improvement Organizations (QIO's)**

In New England there are four QIO's that cover the six states. These organizations hold CMS Medicare contracts to address quality of care in several clinical settings (hospitals, nursing homes and professional offices). The Network has a working relationship with each QIO in this region. Network #1 staff has given articles and presentations to QIO customers in different settings. The sub-national CMS/CKD contract was awarded to 10 QIO's. One was to Quality Partners of Rhode Island. This CKD effort has increased the working relationship with the RI QIO. The Network has several representatives on their CKD strategic coalition.

➤ **End of Life Coalition (EOL)**

This coalition was established in 2005 as one of the CMS special funded projects in 2005/2006. The funding was awarded to the Mid-Atlantic renal coalition (Network #5). The coalition continues to function with no special funds due to the volunteer efforts of several professionals. The mission of the coalition is to promote effective interchange between patients, families, caregiver, payers and providers in support of integrated patient centered end of life care of chronic kidney disease patients. The Network Director of the Network of New England has and continues to serve one of the steering committees for this coalition. In July 2008, the EOL Coalition hosted a strategic planning meeting in Washington DC to prepare for the new ESRD Conditions for Coverage. The coalition was one of the driving forces in getting advance directives acknowledged in the new conditions. The Network #1 Executive Director presented on the study results of the CMS special project on withdrawal from dialysis and hospice utilization. The coalition website has also been expanded and is an excellent resource (www.kidneyeol.org).

➤ **National Kidney Foundation Affiliates (NKF)**

There were three NKF affiliates in New England. During 2008, the National Kidney Foundation has instituted a new organizational structure. The Maine NKF and CT NKF have become subsidiaries of the MA NKF. Both Maine and Connecticut have retained their local office and staff. The Network #1 Director serves on the Medical Advisory Board and the Patient Services Manager serves on the Racial Disparities Committee for the Connecticut NKF. The Network provides data to all three NKF offices upon request.

➤ **Collaboration with Other Network Organizations**

All Networks Organizations participate in the group discipline activities throughout the year. Each group, Network Directors, Quality Managers, Data Managers, and Patient Services Coordinators conduct annual educational programs, participate in quarterly conference calls and routinely share tools and materials developed at the local level with their peers.

Network of New England has been in leadership roles in many of these groups:

- Network #1 Executive Director was the two-year chairperson for Directors and continues to assist the new chair
- Network #1 Patient Services Coordinator was chair in 2008.

➤ **Network of New England Website**

Networks are urged to maintain a website as an important way to provide community outreach and an educational resource. The Internet has become an essential part of all comprehensive communications systems for organizations seeking two-way access to their target audience. Over the past several years, the Network of New England website has been reorganized to allow for greater accessibility and downloading of data. Periodical updates and improvements to the site are done internally with the aid of technological advancements and trained staff members.

In 2007, the Network of New England redesigned their website to accommodate 508 compliance regulations*. Throughout 2008, the Network site continued to be enhanced with new postings, useful links and by providing informative downloads in the following areas:

- | | |
|-----------------------------------|----------------------------------|
| - Annual Report | - Network Goals |
| - Conditions for Coverage | - Network Meeting Information |
| - CROWNWeb | - Network Staff Directory |
| - Data Reporting Forms | - Patient Services and Community |
| - Dialysis Facility Compare (DFC) | - Performance Index |
| - Emergency Preparedness | - Quality Improvement |
| - ESRD Related Publications | - Statistical Highlights |
| - ESRD Network Organizations | - Network Notes Newsletter |
| - Fistula First Initiative | - What's New |
| - Grievance Policy | |

* *Section 508, an amendment to the United States Workforce Rehabilitation Act of 1973, is a federal law mandating that all electronic and information technology developed, procured, maintained, or used by the federal government be accessible to people with disabilities.*

Table M illustrates the number of visits to the Network of New England website, number of pages viewed (hits) and the number of files downloaded for educational purposes during each month of 2008. It is recognized that an increase in web “traffic” occurred in the months prior to the Network Annual Educational Meeting, which takes place in October, when brochures and meeting information are posted. Also identified is an increase in downloaded files following the Annual Meeting when speaker materials are available online. Other noted peaks can be contributed to specific projects, such as the Technician’s Meeting held April of 2008 and quarterly Fistula First updates. Dips in hits and downloads have been documented during the summer months for several years. There has been no definitive explanation for this occurrence other than possible shifts in the staff and patient populations as a result of vacations usually taken during this time in the New England area.

Table M: 2008 Network of New England website Trends

Month	Site Visits	Hits	Downloaded Files
January	2,984	24,091	4,134
February	2,652	25,293	4,537
March	2,793	25,565	4,465
April	3,796	<i>No Data</i>	<i>No Data</i>
May	5,232	43,138	7,536
June	5,269	39,538	6,549
July	5,043	43,208	7,404
August	4,357	41,174	6,852
September	4,053	52,345	<i>No Data</i>
October	5,347	64,097	9,936
November	4,871	55,259	9,361
December	4,585	40,827	9,159

Source: Gamewood, Inc. ESRD Network Organization monthly website trend reports

➤ **Achieving Network #1 Goals in Collaboration with Other Organizations**

Partnerships with ESRD providers and renal professionals have taken many shapes during the past 32 years of this Network. The Patient Advisory Committee is now 10 years old and many of its members serve on different Network #1 Committees. The PAC advice and viewpoint is always valued. The Connecticut Coalition of Organ and Tissue Donation (Donate Life) is 23 years in existence. The addition of a part-time program manager for Donate Life has greatly enhanced the activities and accomplishments of Donate Life Connecticut. The Network #1 annual meeting and newsletters have become a regional tradition. Emergency coordination and regional planning continues to require identification of new partners for updating an effective plan; a challenge the Network accepts.