

NORTH AMERICAN
HOME PARENTERAL AND ENTERAL NUTRITION
PATIENT REGISTRY

ANNUAL REPORT
WITH OUTCOME PROFILES
1985 - 1992

SPECIAL FEATURE
AN ANALYSIS OF HEN CLINICAL OUTCOME
IN PATIENTS WITH NEUROMUSCULAR
DISORDERS OF SWALLOWING

1994

The Oley Foundation

Albany, New York

NORTH AMERICAN HOME PARENTERAL AND ENTERAL NUTRITION PATIENT REGISTRY

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Introduction

This is the eighth annual report of the North American Home Parenteral and Enteral Nutrition Patient Registry and the third annual report to use a longitudinal analysis format. It presents the clinical experience of Registry patients from 1985 to 1992. A special feature of this report is a more extensive analysis of HEN patients with neuromuscular disorders of swallowing. In addition, three HPN diagnostic groups have now accumulated sufficient patient numbers to break them out of the "Other" category and include separate clinical outcome profiles. The three HPN groups are patients with cystic fibrosis, chronic pancreatitis and hyperemesis gravidarum.

Participating Programs

The registry is in effect a large joint research enterprise which attempts to characterize clinical outcome for a wide range of North American patients at home on nutrition support therapy. Once collated and described, these data are available to all clinicians advising patients and their families about the benefits and risks of HPEN treatment. The analyzed, tabulated or raw data are also available to individuals doing primary research on HPEN, once their project is approved by the Oley Foundations's Registry Advisory Committee.

Collecting annual data is in many respects a tedious and time consuming task, particularly for the individuals responsible for the annual extraction of chart-based information. The 223 programs that have participated in this task are listed in Table I below. Over the years, many programs have been regular contributors of information even through several have undergone organizational and name changes. Some programs have dropped out and new ones have entered. Table I indicates the years each program has participated. Programs that reported 1992 data had the option of including the names of the responsible physicians. This table of HPEN programs and physicians provides useful information for those who wish to locate experienced physicians and programs in specific geographic locations.

Table I.
North American Home Parenteral and Enteral Nutrition Patient Registry
Participating Programs / Institutions / Physicians

UNITED STATES PROGRAMS

State	City	Years	Programs / Institutions*	Physicians**	
AL	Birmingham	86-89	Baptist Medical Center-Princeton	<i>Ronald L. Weinsier, Donna ChrisAnderson-Hill, Donald D. Hensrud, Sarah L. Morgan, Louis J. Wilson</i>	
		89-90	The Children's Hospital of Alabama		
		85-92	University of Alabama		
	Prattville	87-90	Unicare /I.V.Services		
AK	Anchorage	90-92	Pediatric Consultants of Alaska		<i>Clinton B. Lillibridge</i>
		86-92	Providence Hospital		
AR	Little Rock	87-88	Alliance Homecare Infusion	<i>V. Suzanne Klimberg</i>	
		86	Baptist Medical Center		
		86-92	University Hospital of Arkansas		
AZ	Phoenix	90-92	Critical Care America		<i>Richard Carmona, Joel Childers, Mary Jo Ghory, Charles Krone, Thomas Daniel, Steven Wool</i>
		87-88	Integrated Medical Specialties		
	Tucson	85, 89-92	Tucson Medical Center		
		85, 89	University Medical Center		
CA	Chico	85-89	OPTION Care	<i>Marvin Ament, Jorge Vargas</i>	
		89	Cedars-Sinai Medical Center		
		85-91	Children's Hospital of Los Angeles		
		84-92	UC-Los Angeles Medical Center		
	Los Angeles				

* During participation in the registry, a number of programs, institutions and service companies have changed their names and locations. If this listing contains errors or is not current, we apologize and ask you to please notify us. - Editors.

** The physicians listed are only those who indicated their interest in being identified in the report of 1992 data. Where identified to us, the director /co-directors of nutrition support programs are given first. Otherwise, alphabetic order is used.

North American Home Parenteral and Enteral Nutrition Patient Registry Participating Programs / Institutions / Physicians (continued)

UNITED STATES PROGRAMS (continued)

State	City	Years	Programs / Institutions*	Physicians**
CA (continued)	Orange Sacramento	87-92	UC-Irvine Medical Center	
		87	NMC Homecare	
	San Diego	85-86, 91	UC-Davis Medical Center	
		88-90	U.S. Naval Hospital	
	San Francisco	84-89	UC-San Diego Medical Center	
		89	Pacific Presbyterian Medical Center	
	San Jose Santa Fe Springs Stanford	85-88	UC-San Francisco	
		85-91	Santa Clara Valley Medical Center	
		87	Abbott Homecare	
		86	Stanford University Medical Center	
CO	Denver	85-92	P/SL Health Care Systems (St. Luke's Hospitals)	<i>Thomas J. McGonagle, Thomas Overett, Howard P. Sherr</i>
		85-89	The Children's Hospital	
	Greeley	90	North Colorado Medical Center	
CT	Pueblo	87-89	Saint Mary-Corwin Hospital	
	New Haven	85-91	Yale University/ New Haven Hospital	
DC	Washington	87-88	Children's National Medical Center	
		86-89	Howard University Hospital	
		86-88	Veterans Administration Med. Center	
		85-90	Washington Medical Center	
FL	Dunedin	87-89	Mease Hospital	<i>C. Richard Fleming Donald E. George</i>
		84-88	Transmed Medical, Inc.	
	Fort Lauderdale Gainesville	85-86	Shands Hospital	
		87-88, 90-92	Mayo Clinic-Jacksonville	
	Jacksonville	90-92	Nemours Childrens Clinic	
		89	Orlando Regional Medical Center	
Orlando Tampa	88-92	H. Lee Moffitt Cancer Center	<i>Jay J. Mamel,</i>	
	86-91	Tampa General Hospital		
GA	Atlanta	89-92	St. Joseph's Hospital of Atlanta	<i>Diane K. Smith</i>
	Augusta	85-92	Medical College of Georgia	
HI	Honolulu Tripler AMC	88	Caremark	
		87	Tripler Army Medical Center	
IL	Chicago	85-86	Home Hyperalimentation Service	<i>Robert Kushner, Michael D. Sitrin, Charles Baum</i>
		92	Northwestern Memorial Hospital	
		85-92	University of Chicago Medical Center	
		89	Wyler Children's Hospital	
	Chillicothe	89-91	Home IV of Central Illinois	
		86	Alexian Brothers Home Health	
	Elk Grove Village	85-89	Veterans Administration Hospital	
		87-90	Saint Joseph Medical Center	
	Hines	87-88	NMC Homecare	
		87-88	Abbott Home Care	
	Joliet	85-87	North Chicago VA Medical Center	
		86-89, 91-92	Saint Francis Medical Center	
	Morton Grove	90-91	Rockford Gastroenterology Associates	
		86-91	Rockford Memorial Hospital	
	Mount Prospect	86-89, 91-92	Saint Anthony Medical Center	
		86, 88	Saint John's Home Infusion Therapy	
	North Chicago	87	Community General Hospital	
89		OPTION Care		
Peoria	86-91	Carle Foundation Hospital		
	86-91			
Rockford	87-91	Indianapolis Gastroenterology	<i>Michael T. Isenberg, Edward V. Schultz, Vance V. VanDrake</i>	
	85-92	Indiana Regional Medical Consultants		
IN	Beech Grove	87-91		
	Fort Wayne	85-92		
	South Bend	90-92	Saint Joseph Medical Center	
IA	Iowa City Ottumwa	90	University of Iowa Hospital	
		90	McWilliams OPTION Care	
KS	Kansas City	88	Care Plus	

North American Home Parenteral and Enteral Nutrition Patient Registry Participating Programs / Institutions / Physicians (continued)

UNITED STATES PROGRAMS (continued)

State	City	Years	Programs / Institutions*	Physicians**	
LA	Houma	90-91	OPTION Care	<i>James Smith, Teresa Zimmerman</i>	
	Lafayette	84-87	Caremark		
	Lake Charles	89-90	Lake Charles Infusion Care		
	New Orleans	85-88	Medical Center of East New Orleans		
		92	Ochsner Foundation Hospital		
ME	Falmouth	87-88	Hospital Home Health Care, Inc.		
MD	Annapolis	85-87	Anne Arundel Medical Center	<i>Louis Dennis, Richard DiGioia, Laurence McDonald</i>	
	Baltimore	86	Bashar Pharoan, M.D.		
		87	University of Maryland Medical System		
	Silver Spring	91-92	Pharmacy Corporation of America		
MA	Boston	85-87	Beth Israel Hospital	<i>Douglas W. Wilmore, Danny O. Jacobs, Thomas Morrissey, Thomas Nattakom Clifford Lo</i>	
		89-92	Brigham & Women's Hospital		
		85, 87-92	Children's Hospital		
		88	Dana Farber Cancer Institute		
			84-92	New England Deaconess Hospital	<i>George Blackburn, Edward Mascioli Garry F. Fitzpatrick, Robert H. Lerman</i>
			86-92	University Hospital / Boston University	
			89-91	Abbott Home Care Program	
		Melrose	88	Berkshire Health-at-Home	
		Pittsfield	89-92	Chartwell Home Therapies	
		Waltham			
MI	Ann Arbor	85-92	University of Michigan Hospital	<i>Jason H. Bodzin</i>	
		85-86	Henry Ford Hospital		
		85-92	Sinai Hospital		
		85-91, 86-92	Harper Hospital		
		Grand Rapids	86-92	Butterworth Hospital	<i>James D. Paauw, David E. Scheeres, Donald J. Scholten</i>
		Lansing	86-89	MHC Health Quest Infusion Therapies	<i>Kari Hortos</i>
		Mount Clemens	86-88, 90-91	Mount Clemens General Hospital	
	Southfield	85-92	Providence Hospital	<i>Lawrence P. Zablocki, Steven Miles</i>	
	Traverse City	92	Munson Medical Center		
MN	Minneapolis	85-89	University of Minnesota Hospital	<i>Darlene G. Kelly, Daniel L. Hurley, W. Fredrick Schwenk</i>	
	Rochester	84-92	Mayo Clinic		
MO	Saint Louis	86-90	American Home Therapies (Jewish Hospital at Washington University)	<i>Robert Wright</i>	
		89-92	Deaconess Hospital		
		85, 87-91	Saint Louis University Hospital		
NE	Lincoln	86-91	Bryan Memorial Hospital		
		85-89	Critical Care America		
		86-87	Methodist Hospital		
		85,87-89	University of Nebraska Med. Cntr.		
NJ	Edison	91	Critical Care America		
	Newark	87-88	University Hospital / UMDNJ		
	Totowa	87-88	Critical Care America		
NY	Albany	84-92	Albany Medical College	<i>Lyn Howard, Shahab Aftahi, Sharon Alger, James Betzhold</i>	
		89-90	Equicare		
			89-92	Veterans Administration Medical Center	
		Binghamton	85-91	Twin Tier Home Health, Inc.	<i>Frank Booth, Robert Moscovitz</i>
		Buffalo	87-88, 90-92	Buffalo General Hospital	
			86	Children's Hospital of Buffalo	
			85-87	Vital Care (Millard Filmore Hospital)	
			90	Syncor Homecare Services	
		Cohoes	90	North Shore University Hospital	
		Manhasset	89-90	Winthrop University Hospital	
		Mincola	87-88	North Westchester Hospital Center	
		Mount Kisko	84-92	Memorial-Sloan Kettering Institute	
		New York	86-90	Memorial-Sloan Kettering Institute	
			88-89	Saint Luke's / Roosevelt Hospital	

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