

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

\* 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	87-92	UC-Irvine Medical Center	
	Sacramento	87	NMC Homecare	
		85-86, 91	UC-Davis Medical Center	
	San Diego	88-90	U.S. Naval Hospital	
		84-89	UC-San Diego Medical Center	
	San Francisco	89	Pacific Presbyterian Medical Center	
		85-88	UC-San Francisco	
	San Jose	85-91	Santa Clara Valley Medical Center	
	Santa Fe Springs	87	Abbott Homecare	
	Stanford	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>
	Fort Lauderdale	84-88	Transmed Medical, Inc.	
	Gainesville	85-86	Shands Hospital	
	Jacksonville	87-88, 90-92	Mayo Clinic-Jacksonville	
		90-92	Nemours Childrens Clinic	
	Orlando	89	Orlando Regional Medical Center	
	Tampa	88-92	H. Lee Moffitt Cancer Center	
		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	88	Caremark	
	Tripler AMC	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	<i>R. Michael Gulley</i>
	Elk Grove Village	86	Alexian Brothers Home Health	
	Hines	85-89	Veterans Administration Hospital	
	Joliet	87-90	Saint Joseph Medical Center	
	Morton Grove	87-88	NMC Homecare	
	Mount Prospect	87-88	Abbott Home Care	
	North Chicago	85-87	North Chicago VA Medical Center	
	Peoria	86-89, 91-92	Saint Francis Medical Center	
	Rockford	90-91	Rockford Gastroenterology Associates	
		86-91	Rockford Memorial Hospital	
	Springfield	86-89, 91-92	Saint Anthony Medical Center	<i>Charles Welford</i>
		86, 88	Saint John's Home Infusion Therapy	
		87	Community General Hospital	
		89	OPTION Care	
	Sycamore	86-91	Carle Foundation Hospital	
	Urbana			
IN	Beech Grove	87-91	Indianapolis Gastroenterology	<i>Michael T. Isenberg, Edward V. Schultz, Vance V. VanDrake</i>
	Fort Wayne	85-92	Indiana Regional Medical Consultants	
	South Bend	90-92	Saint Joseph Medical Center	
IA	Iowa City	90	University of Iowa Hospital	
	Ottumwa	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	
	Melrose Pittsfield Waltham	86-92	University Hospital / Boston University	<i>George Blackburn, Edward Mascioli Garry F. Fitzpatrick, Robert H. Lerman</i>
		89-91	Abbott Home Care Program	
		88	Berkshire Health-at-Home	
		89-92	Chartwell Home Therapies	
MI	Ann Arbor Detroit	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 Mount Clemens	86-89	MHC Health Quest Infusion Therapies	<i>Kari Hortos</i>
		86-88, 90-91	Mount Clemens General Hospital	
	Southfield Traverse City	85-92	Providence Hospital	<i>Lawrence P. Zablocki, Steven Miles</i>
		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 Omaha	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 Buffalo	85-91	Twin Tier Home Health, Inc.	<i>Frank Booth, Robert Moscovitz</i>
		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	<i>(parenteral) (enteral)</i>
	Manhasset	89-90	Winthrop University Hospital	
	Mineola	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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