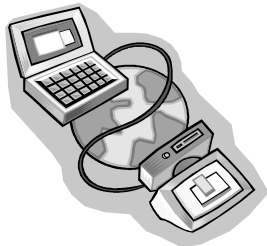


REGISTRY NEWS

Volume 10 Newsletter for the Pediatric Cardiomyopathy Registry Winter/Spring 2000



PCMR MOVES INTO CYBERSPACE!

<https://www.neri.org/pcmr>

Today's technological advances promise to bring some exciting changes to the Pediatric Cardiomyopathy Registry! We are pleased to announce that the programming staff at New England Research Institutes has developed and is currently in the process of testing a web-based data management system for PCMR. NERI's cutting-edge proprietary data management system is called ADEPT (Advance Data Entry and Protocol Tracking). This system is a JavaScript-based enhancement of the system that was described in Volume 7 of Registry News.

The software design of ADEPT is multi-tiered, and utilizes Oracle 8 database servers and Microsoft IIS 4.0 Web servers. The security of ADEPT is state of the art, employing an approach comparable to that used in electronic commerce. Access is only allowed via assigned user names and passwords, and is monitored and restricted using a firewall. All communication is encrypted using secure socket layer protocols.

Among the many benefits of this new system, ADEPT will allow sites with browser-equipped PCs or Macs to enter PCMR data directly onto the computer, thus reducing the copying and postage costs incurred from using paper forms. Internet-ready sites will be given a unique login and password that, when entered on the PCMR website, will allow them exclusive viewing of their own data. Using ADEPT, sites will be able to view the status of all of their patients, and thus be able to determine at the click of a mouse what forms are outstanding or incomplete. The electronic versions of the forms will appear virtually identical to the current paper versions, making data entry in ADEPT as simple as filling out a paper form.

Helpful links and instructions for completing the forms will be readily accessible on this new system, furthering the ease of the data entry process. During the entry of forms, ADEPT will perform validity checks on each field, and the user will immediately be notified of any questionable values or incomplete responses. As a result, the user will have the option to respond to any edits on the spot, while the patient's medical record is in front of him or her, rather than waiting for paper edit reports to be generated and sent out by the Data Coordinating Center.

This new web-based system will also allow our Outreach Team of data collectors to operate at peak efficiency. If a visit to your site is scheduled later this year, please give some thought to arranging workspace with Internet access for Outreach Team members to use for data entry during their visit.

In March the Outreach Team of data collectors completed a very successful ADEPT training session held at NERI. Be on the lookout for further news regarding the new PCMR ADEPT data management system - sometime in May you should receive your site's login and password along with instructions for using the system. In the meantime, you can check out the new PCMR informational web site at <https://www.neri.org/pcmr>. This web site contains updates about the Registry, recent newsletters and publications, various links to other pediatric cardiomyopathy web sites, and FAQs (Frequently Asked Questions). We are excited to share these new technologies with you and hope that you share our enthusiasm as PCMR progresses into the 21st century!



INSATIABLE CURIOSITY

Please forgive me for another motivational lecture! We can all breathe easier knowing that the PCMR is funded until the end of August, 2000 and that there is a reasonable chance that it will do well at the coming competitive renewal. How should we be adjusting ourselves to this second wind, this vote of confidence from the NHLBI? Obviously, we must continue the good habits already formed for recruitment and retention of patients and data entry.

Beyond that, bearing in mind that one of the aims of the grant that supports the Registry is a reduction in the number of idiopathic cases, we must make an extra effort to communicate to our colleagues an obligation to get etiologic answers. Newsletter No. 2 and the accompanying reprint provided diagnostic algorithms for genetic and metabolic cardiomyopathies and No. 5 identified laboratories equipped to analyze materials for these diagnoses. I wonder if these are gathering dust on top of your filing cabinet, or have they been copied and distributed to all the cardiologists in your group? This is a gentle reminder.

Once infectious and metabolic and the more obviously genetic causes are eliminated, "isolated" cardiomyopathy remains. That is not much closer to an etiologic diagnosis than "idiopathic". As we are now well aware, when these have occurred in kindreds they have sometimes been subjected to analysis resulting in determination of the responsible gene. Stay alert to these possibilities and enlist the cooperation of a well-equipped genetics lab. Sooner or later, the science of the cardiomyopathies will be increased through your vigilance AND the patients' families will have answers that may become prophylactically or therapeutically beneficial.

Another route to increasing our understanding is the collection and preservation of tissue and blood even though it may not seem immediately useful. Certainly when a heart is explanted or exposed at an autopsy performed at the earliest possible moment the opportunity should not be missed for taking myocardial samples and preserving them by snap freezing, formalin and glutaraldehyde for EM. You will need proactively to motivate your pathologist who will need to provide technical help with the samples and storage space. When support for the tissue bank to be keyed to the Registry clinical data is obtained, there will be a central repository for such material, but let us not lose any valuable potential information in the meantime.

The NHLBI trusts that we, the pediatric cardiologists of the USA and Canada, will advance the understanding of the pediatric cardiomyopathies by pursuing each of the patients in our centers with INSATIABLE CURIOSITY! Their families will applaud and support our efforts.

Paul R. Lurie, MD

Data Manager:

Rebecca Orfaly
(617) 923-7747 ext. 367
rorfaly@neri.org

PI:

Lynn Sleeper, Sc.D.
(617) 923-7747 ext. 235
lynnns@neri.org

Statistician:

April Lowe, M.S.
(617) 923-7747 ext. 545
alowe@neri.org

Research Assistant:

Alejandro Cajigal
(617) 923-7747 ext. 525
acajigal@neri.org

REGISTRY NEWS

Staff

Editor

Alejandro Cajigal, BA

Co-Editor

Paul Lurie, MD

Contributors

Administrative Coordinating Center
Steven Lipshultz, MD

New England Coordinating Center

Steven Colan, MD

Gerald Cox, MD

Jane Messere, RN

Eran Muto, BS

Kristina McCoy, BS

Ahmet Guler, BA

Central Southwest Coordinating Center

Jeffrey Towbin, MD

Data Coordinating Center

Lynn Sleeper, ScD

April Lowe, MS

Rebecca Orfaly, BS

Alejandro Cajigal, BA

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DATA MANAGER CORNER

The following are a few important things to remember before sending data to the DCC:

❶ Make sure that you answer **ALL** questions on the data collection forms, even if the answer is "No". If for some reason you cannot answer a question, please write a brief explanation in the margin as to why you left it blank. Edit reports are a nuisance for all of us, and by taking a little extra care during the form completion process, we can hopefully reduce the number generated.

❷ Please note that we have made some changes to the Supplemental Form (02), the Annual Form (03), and the Lost to Follow-up/Transfer Forms (05/06). Included in these changes is the **addition of several echo questions (EF, EDV, ESV)**. Also, in order to ensure that we classify the data in the most accurate possible manner, we have added a number of **additional diagnosis and**

pathology codes. Finally, we have combined the Lost to Follow-up Form (05) and the Transfer Form (06) into one straightforward, two-page form (see below for more information).

❸ Finally, if any questions arise when you are filling out PCMR forms, whether they be regarding the eligibility of a patient or how to respond to a particular question, **please feel free to contact me at the Data Coordinating Center (Rebecca at 617-923-7747x367, rorfaly@neri.org)**. Remember: we're here to help things go as smoothly as possible!

FREQUENT QUESTIONS ... ANSWERED!



It has come to my attention that there is some confusion surrounding the process of declaring a patient enrolled in the Registry lost to follow-up. For this reason, in combination with the fact that we have recently made some changes to Form 05, I have provided some helpful tips below. You will receive copies of all of the newly revised forms in the next few weeks. If you have any other questions regarding this issue or form completion in general, please feel free to contact me at any time (Rebecca at 617-923-7747x367, rorfaly@neri.org).

Q: *Upon reviewing an enrolled patient's medical record in preparation to fill out an annual Form 03, I noticed that the patient had missed his last clinic visit, and thus was not seen during the reporting period indicated on the form. Should I declare this patient lost to follow-up?*

A: You should NOT declare this patient lost to follow-up at this point. According to PCMR protocol, a patient must miss two consecutive clinic visits before they can be declared lost. Instead, you should report on Form 03 (Question A8 on the Prospective [short] form, Question A9 on the Retrospective [long] form) that the patient was not seen during the reporting period in question. Select 4 = "Other" as the reason why there was no contact, and write in the space provided that the patient missed their annual clinic visit.

Q: *An enrolled patient has missed two consecutive clinic visits. I have no record of this patient being seen at our site or any other hospital for over two years. After numerous attempts, his primary cardiologist has not been able to contact this patient nor his family. Should I declare this patient Lost to Follow-up?*

A: Yes, this patient should be declared Lost to Follow-up. When completing the next annual form for this patient, you should report that the patient was not seen

during the reporting period in question. Select 2 = "Lost to Follow-up" as the reason why there was no contact. Subsequently, a pre-labeled Form 05 will be sent to you, please complete this form to the best of your ability and return it to the Data Coordinating Center.

Q: *I've heard that there have been some changes to Form 05. What is the purpose of this form and when do I need to fill it out?*

A: Form 05, previously called the Lost to Follow-up Form, was expected for all patients who had been declared lost to follow-up or whose care was transferred to another medical institution. For patients whose care was transferred to another institution, Form 06, the Transfer Form - was also expected. We have simplified this process by combining the data that was previously collected on these two forms onto one. This new Form 05 is now called the Lost to Follow-up/Transferred/Discharged from Follow-up Form. It will now be expected for all patients who are reported lost, transferred, or discharged on Form 03. By combining this information onto one form, we hope to simplify both the data collection process for you as well as the data analysis process.

RECENT ABSTRACTS



Design and Implementation of the North American Pediatric Cardiomyopathy Registry

Michelle A. Grenier, MD; Stavroula K. Osganian, MD, MPH; Gerald F. Cox, MD, PhD; Jeffrey A. Towbin, MD; Steven D. Colan, MD; Paul R. Lurie, MD; Lynn A. Sleeper, ScD; E. John Orav, PhD; and Steven E. Lipshultz, MD

The Pediatric Cardiomyopathy Registry (PCMR) was established to describe the epidemiologic features and clinical course of selected cardiomyopathies in patients aged 18 years or younger and to promote the development of etiology-specific treatments. Sixty-one private and institutional pediatric cardiomyopathy practices in the United States and Canada were recruited to participate in the PCMR. The Registry consists of a prospective, population-based cohort of patients in 2 regions (New England and the Central Southwestern United States) and a retrospective cohort of patients diagnosed

between 1991 and 1996. Annual follow-up data are collected on all patients. As of June 1999, the PCMR consisted of 337 prospectively identified and 990 retrospectively identified patients. The PCMR has demonstrated the feasibility of establishing a large database of sociodemographic and clinical information on children with pediatric cardiomyopathy. Through this cooperative effort, the PCMR will obtain precise estimates of the incidence of pediatric cardiomyopathy and a better understanding of the natural history of the disease.

[*American Heart Journal* 2000; 139:S86-S95.]

Outcomes For Children With Cardiomyopathy Awaiting Transplantation

Lynne E. Nield MD, FRCP(C), Brian W. McCrindle MD, MPH, FRCP(C), FACC, Desmond J. Bohn MB, BCh, FRCP(C), Lori J. West MD, D. Phil, FRCP(C), John G. Coles MD, FRCS(C), Robert M. Freedom MD, FRCP(C), FACC, Lee N. Benson MD, FRCP(C), FACC

Objective: To determine factors associated with outcomes after listing for transplantation in children with cardiomyopathies.

Background: Childhood cardiomyopathies form a heterogeneous group of diseases, and in many, the prognosis is poor, irrespective of the etiology. When profound heart failure develops, cardiac transplantation can be the only viable option for survival.

Methods: All pediatric patients with cardiomyopathy listed for transplantation between 12/89 and 4/98 were included in this historical cohort study.

Results: Thirty-one patients (15 male, 16 female) with either dilated (n=27) or restrictive (n=4) cardiomyopathy were listed for transplantation. Median age at listing was 5.7 years (range: fetal to 17.8 years). Median interval from listing to transplantation (n=23) was 54 days (range: 0 to 11.4 years), with 14 patients

transplanted <30 days after listing. Five patients (16%) died before transplantation (1 status III; 4 status IV, Canadian algorithm), 23 (74%) were transplanted, with 1 removed from the list after 12 days (recovered myocarditis) and 2 awaiting transplantation (after 121 and 476 days). Patients who died were more likely to be female 5/5 vs. 11/26; p=0.04) and be status III or IV at listing (5/5 vs. 15/26; p=0.04). The use of mechanical ventricular assist (n=10) was not a predictor of an adverse outcome. While not statistically significant, survival to transplantation was associated with ACE inhibitor therapy, those with less mitral regurgitation, a higher mean ejection fraction and cardiac index, and lower right ventricular systolic pressure.

Conclusions: Children with cardiomyopathy awaiting transplantation have a mortality of 16% related to status at listing.

[*Cardiol Young* 2000; 10(4): in press]

RECENT ABSTRACTS, *Continued*



Molecular Heterogeneity in Very-Long-Chain Acyl-CoA Dehydrogenase Deficiency Causing Pediatric Cardiomyopathy and Sudden Death

Amit Mathur, MBBS, MD, MRCP; Harold F. Sims, BA; Deepika Gopalakrishnan, MBBS, MD; Beverly Gibson, BS; Piero Rinaldo, MD; Jerry Vockley, MD, PhD; George Hug, MD; Arnold W. Strauss, MD

Background: Genetic defects are being increasingly recognized in the etiology of primary cardiomyopathy (CM). Very-long-chain acyl-CoA dehydrogenase (VLCAD) catalyzes the first step in the β -oxidation spiral of fatty acid metabolism, the crucial pathway for cardiac energy production.

Methods and Results: We studied 37 patients with CM, nonketotic hypoglycemia and hepatic dysfunction, skeletal myopathy, or sudden death in infancy with hepatic steatosis, features suggestive of fatty acid oxidation disorders. Single-stranded conformational variance was used to screen genomic DNA. DNA sequencing and mutational analysis revealed 21 different mutations on the VLCAD gene in 18 patients. Of the mutations, 80% were associated with CM.

Severe CM in infancy was recognized in most patients (67%) at presentation. Hepatic dysfunction was common (33%). RNA blot analysis and VLCAD enzyme assays showed a severe reduction in VLCAD mRNA in patients with frame-shift or splice-site mutations and absent or severe reduction in enzyme activity in all.

Conclusions: Infantile CM is the most common clinical phenotype of VLCAD deficiency. Mutations in the human VLCAD gene are heterogeneous. Although mortality at presentation is high, both the metabolic disorder and cardiomyopathy are reversible.

[*Circulation* 1999; 99:1337-1343.]

Hypertrophic Cardiomyopathy and Premature Death in the Young: The Histological Characteristics of Patients Aged 21 Years and Under

Amanda M. Varnava, Perry M. Elliot, Niall Mahon, William J. McKenna, Michael J. Davies

Background: Premature death is a significant risk in patients with HCM, especially in the young. It is likely that the mechanisms of death in these patients is different from the adult population, however little is known of the pathological findings in this group. We examined in detail the histology of patients aged 21 years and under and correlated these results with the clinical findings.

Methods: The symptoms, echo data and risk profile were noted in 18 HCM patients 21 and under who had suffered sudden cardiac death (SCD) or cardiac failure. Hearts were weighed after fixation and % fibrosis, % disarray and degree of small vessel disease noted in 6 sections (LV anterior, posterior and lateral free wall, anterior and posterior septum, and RV free wall), at 3 levels (base mid section and apex). Pathological data were compared to HCM patients over 21 years (range 22-72 years).

Results: There were 12 males, 6 females, mean age 14.6 years (range 6-21). 10 suffered premonitory symptoms, including syncope in 3. 7

of 7 had an abnormal ECG, 1 of 7 had a resting gradient on echo, none of 4 had NSVT on holter and 4 of 4 had an abnormal blood pressure response to exercise. 13 suffered SCD. Mean heart weight, % microscopic fibrosis, and small vessel disease did not differ significantly from the adult group. 15% had marked scarring compared to 47% of the adult group, $p = 0.01$, whilst disarray was significantly greater (35.5% vs. 20.7% respectively, $p = 0.002$).

Conclusion: Young patients who die with HCM are characterized by markedly less macroscopic scarring and a greater degree of myocyte disarray. Of those assessed all had an abnormal vascular response. We have previously reported that disarray is not associated with episodes of NSVT, but did correlate with an abnormal vascular response. It is likely that sudden cardiac death in the young is related to hemodynamic collapse rather than fatal arrhythmias.

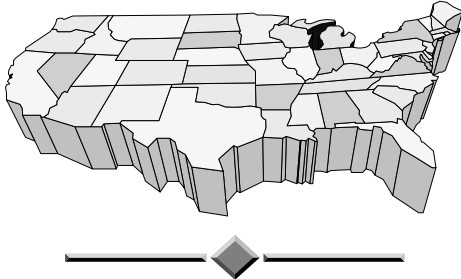
[*J Am Col Card* 2000; 35; 2:191A.]



ENROLLMENT REPORT

PCMR Enrollment as of March 31, 2000 1,959 Eligible Patients

As of March 31, 2000 we have **1,959** eligible patients enrolled in the Registry!



Of the 250 sites that have agreed to participate, the following 92 sites have submitted Enrollment Forms:

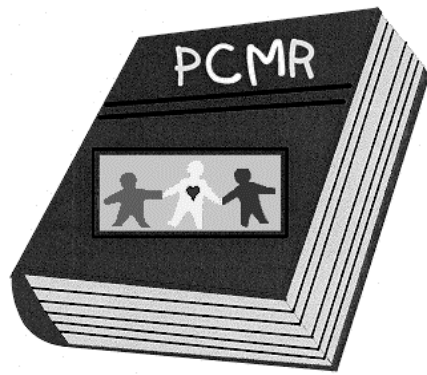
- Site 4: Columbus Children's Hospital, Columbus, OH, *Dr. Hugh Allen*
- Site 5: Cook Children's Heart Center, Fort Worth, TX, *Dr. J. Hudson Allender and Dr. Steve Lai*
- Site 11: Hospital For Sick Children, Toronto, Ontario, *Dr. Lee N. Benson*
- Site 12: Children's Hospital of Wisconsin, Milwaukee, WI, *Dr. Stuart Berger*
- Site 16: Pediatric Cardiology, San Antonio, TX, *Dr. Kenneth R. Bloom*
- Site 20: University of Maryland Medical System, Baltimore, MD, *Dr. Janet N. Scheel*
- Site 24: The Johns Hopkins Hospital, Baltimore, MD, *Dr. Jean Kan and Dr. Janet Scheel*
- Site 25: The Children's Heart Clinic, Minneapolis, MN
- Site 28: Connecticut Children's Medical Center, Hartford, CT, *Dr. Harris Leopold*
- Site 39: NYU Medical Center, New York, NY, *Dr. Michael Artman and Dr. Dolores Danilowicz*
- Site 41: Vanderbilt University, Pediatric Cardiology, Nashville, TN, *Dr. Debra Dodd*
- Site 43: University of Vermont, Burlington, VT, *Dr. Nancy A. Drucker*
- Site 44: University of Alberta Hospital, Edmonton, Alberta, *Dr. John Dyck*
- Site 47: Children's Hospital of Michigan, Detroit, MI, *Dr. Robert Ross and Dr. Zia Farooki*
- Site 48: Children's Heart Center of Las Vegas, Las Vegas, NV, *Dr. William N. Evans*
- Site 54: Dartmouth-Hitchcock Medical Center, Lebanon, NH, *Dr. Nancy Drucker*
- Site 56: Arkansas Children's Hospital, Little Rock, AR, *Dr. Elizabeth Frazier, Dr. Paul Seib, and Dr. Robert Morrow*
- Site 58: University of Florida, Gainesville, FL, *Dr. F. Jay Fricker and Dr. Barry Byrne*
- Site 60: Mount Sinai Medical Center, New York, NY, *Dr. Bruce D. Gelb*
- Site 62: Children's Hospital, Buffalo, NY, *Dr. Robert L. Gingell*
- Site 65: Alberta Children's Hospital, Calgary, Alberta, *Dr. David Patton*
- Site 68: Marshall University School of Medicine, Huntington, WV, *Dr. Mahmood Heydarian*
- Site 69: Children's Hospital of Eastern Ontario, Ottawa, Ontario, *Dr. Martin Hosking*
- Site 72: BC Children's Hospital, Vancouver, British Columbia, *Dr. Derek G. Human*
- Site 78: Wichita Clinic, Pediatric Cardiology, Wichita, KS, *Dr. Steve Allen*
- Site 82: Loma Linda University Medical Center, Loma Linda, CA, *Dr. Ranae L. Larsen*
- Site 85: Children's Hospital of Los Angeles, Los Angeles, CA, *Dr. Alan B. Lewis*
- Site 86: New York Hospital, New York, NY, *Dr. Myles S. Schiller*
- Site 89: Lincoln Pediatric Cardiology, Lincoln, NE, *Dr. Ameeta Martin*
- Site 91: Boston Floating Hospital, Boston, MA, *Dr. Jonathan Rhodes*
- Site 98: Children's Associated Medical Group, San Diego, CA, *Dr. Kathleen Maginot*
- Site 99: TC Thompson Children's Hospital, Chattanooga, TN, *Dr. John R. Morgan*
- Site 100: Medical College of Virginia, Richmond, VA, *Dr. William B. Moskowitz*
- Site 101: University of Iowa Hospitals and Clinics, Iowa City, IA, *Dr. Mary Jeannette Hagan Morriss*
- Site 104: University of Kentucky College of Medicine, Lexington, KY, *Dr. Bradley B. Keller*
- Site 105: SUNY Health Science Center at Brooklyn, Brooklyn, NY, *Dr. Dov B. Nudel*
- Site 106: Children's Memorial Hospital, Chicago, IL, *Dr. Elfriede Pahl and Dr. Sam Gidding*
- Site 108: Division of Pediatric Cardiology, Sacramento, CA, *Dr. Mark D. Parrish*
- Site 109: University of Texas Medical Branch, Galveston, TX, *Dr. William Pearl*
- Site 110: Tulane University Hospital and Clinic, New Orleans, LA, *Dr. Arthur Pickoff*
- Site 113: Cardinal Glennon Children's Hospital, St. Louis, MO, *Dr. Ian Balfour and Dr. P.S. Rao*
- Site 117: Oregon Health Sciences University, Portland, OR, *Dr. Mark D. Reller*
- Site 119: The Sanger Clinic, Charlotte, NC, *Dr. Donald Riopel*
- Site 121: 3200 SW 60th Ct., Miami, FL, *Dr. Richard Zakheim*
- Site 122: Children's Heart Network, San Antonio, TX, *Dr. James H. Rogers*

ENROLLMENT REPORT

PCMR Enrollment as of March 31, 2000 1,959 Eligible Patients

- Site 124: UCSD Medical Center, San Diego, CA, *Dr. Abraham Rothman*
- Site 125: Children's Cardiology Associates, Austin, TX, *Dr. Stuart A. Rowe*
- Site 129: South Texas Pediatric Cardiology Associates, Corpus Christi, TX, *Dr. John Pastorek*
- Site 135: Children's Hospital of Orange County, Orange, CA, *Dr. Melville Singer*
- Site 139: Capital District Pediatric Cardiology Assoc., Albany, NY, *Dr. Harm Velvis*
- Site 140: Montefiore Medical Center, Bronx, NY, *Dr. Carl N. Steeg*
- Site 142: Washington University School of Medicine, St. Louis, MO, *Dr. Arnold Strauss*
- Site 144: University of Miami School of Medicine, Miami, FL, *Dr. Delores Tamer, and Dr. Grace Wolf*
- Site 148: Texas Children's Hospital, Houston, TX, *Dr. Jeffrey Towbin*
- Site 151: Royal University Hospital, Saskatoon, SK, Canada, *Dr. Michael Tyrrell*
- Site 154: The Children's Heart Center, Atlanta, GA, *Dr. Margaret Strieper*
- Site 158: Children's Hospital Heart Center, Albuquerque, NM, *Dr. J. Deane Waldman*
- Site 161: Rhode Island Hospital, Providence, RI, *Dr. John Werner*
- Site 164: University of Texas Health Science Center, Houston, TX, *Dr. Steve Wolfe*
- Site 168: Children's Hospital, Boston, MA, *Dr. Steven Colan*
- Site 183: Children's Hospital Medical Center, Cincinnati, OH, *Dr. Tom Kimball, Dr. William Lewis, and Dr. David Schwartz*
- Site 184: Primary Children's Medical Center, Salt Lake City, UT, *Dr. Bob Shaddy*
- Site 185: Children's Hospital Pittsburgh, Pittsburgh, PA, *Dr. Steve Webber*
- Site 187: UCLA Children's Hospital, Los Angeles, CA, *Dr. Juan Alejos*
- Site 188: Michigan State University, East Lansing, MI, *Dr. Monica M. Goble*
- Site 189: Yale University, Pediatric Cardiology, New Haven, CT, *Dr. Peter Bowers*
- Site 192: Babies and Children's Hospital, New York, NY, *Dr. Daphne Hsu*
- Site 193: Pediatric Cardiology, Cleveland, OH, *Dr. Maryanne Kichuk*
- Site 195: Duke University Medical Center, Durham, NC, *Dr. Resai Bengur*
- Site 196: Strong Memorial Hospital, Rochester, NY, *Dr. Steven Lipshultz*
- Site 197: East Carolina University School of Medicine, Greenville, NC, *Dr. Michael McConnell*
- Site 199: University of Alabama at Birmingham, Birmingham, AL, *Dr. Bennett Pearce*
- Site 200: Oklahoma Children's Hospital, Oklahoma City, OK, *Dr. Kent Ward*
- Site 201: Children's Medical Center of Dallas, Dallas, TX, *Dr. Matthew S. Lemler*
- Site 203: Metro Health Medical Center, Cleveland, OH, *Dr. David Connuck*
- Site 204: The Children's Heart Center of West Texas, Lubbock, TX, *Dr. Charlie J. Sang, Jr.*
- Site 216: Eastern Main Medical Center, Bangor, ME, *Dr. Angela Gilladoga*
- Site 217: Pediatric Cardiology Associates, Portland, ME, *Dr. Maribeth Hourihan*
- Site 222: Elliot Hospital, Manchester, NH, *Dr. Sol Rockenmacher*
- Site 223: Hasbro Children's Hospital, Providence, RI, *Dr. Robert Corwin*
- Site 224: Pediatric Cardiology, Providence, RI, *Dr. Kelly Strickland*
- Site 226: Presbyterian Professional Building III, Dallas, TX, *Dr. Edgar A. Newfeld*
- Site 227: Wilford Hall Medical Center, Lackland AFB, TX, *Dr. John Brownlee*
- Site 228: Department of Pediatrics, El Paso, TX, *Dr. Jeffrey Schuster*
- Site 229: Mass General Hospital, Boston, MA, *Dr. Baruch S. Ticho*
- Site 232: UMASS Medical Center, Worcester, MA, *Dr. Phyllis Pollack*
- Site 235: Children's Hospital of Montreal, Montreal, Quebec, *Dr. Charles Rohlicek*
- Site 237: University of Illinois Medical Center, Chicago, IL, *Dr. David G. Thoele and Dr. SP Kumar*
- Site 238: Loyola University Medical Center, Maywood, IL, *Dr. Elizabeth Fisher*
- Site 243: UC Irvine Medical Center, Orange, CA, *Dr. Robin Shaughnessy*
- Site 244: PEDIAPEX, Heart Center for Children, Dallas, TX, *Dr. Patrick Callahan*
- Site 245: Healthcare Professional Associates, Amarillo, TX, *Dr. Jorge Garcia*

Please submit your Enrollment Postcards immediately upon identification of each of your cardiomyopathy patients so that our incidence estimates remain up-to-date and accurate. The postcard can then be followed by the Supplemental Form 02 when chart review is complete, preferably within 6 weeks of diagnosis. Your continued contributions strengthen this unique and amazing database!



Registry News

Vol. 10 Newsletter for the Pediatric Cardiomyopathy Registry Winter/Spring 2000

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Insatiable Curiosity

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Registry News

New England Research Institutes, Inc.
9 Galen Street
Watertown, MA 02472
USA

