Iowa Neuromuscular Program

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How Did We Get Here?

- Hans Zellweger (James Hanson, Victor Ionasescu)
  - Identified and conceptualized a need for specialized care for individuals with neuromuscular disease
  - Included genetics, neurology, nursing & physical therapy

- Contract between the UI Dept of Pediatrics & Iowa Department of Public Health in mid 1980’s
  - State appropriations -- $99,799

- Administered under the Center for Congenital & Inherited Disorders Committee (advisory committee to the IDPH)
  - Genetics, newborn screening, birth defects registry, pregnancy screening, other disease-specific conditions.

- Other statewide programs
  - Child Health Specialty Clinics, Regional Genetics Consultation Program, Birth Defects Registry, Area Education Agency, etc.
Purpose Statement

To provide neuromuscular (NM) healthcare services, care coordination & education for individuals/families with NM disease throughout the State of Iowa.

To provide education & information about NM disorders to health care providers, educators and others in the community.
Neuromuscular Population

- NM disorders affect individuals throughout Iowa

- Various NM disorders
  - Muscular dystrophies (>25 types)
  - Myopathies
  - Neuropathies (ex CMT)
  - Neuromuscular junction (ex myasthenia gravis)
  - Movement disorders (Friedreich ataxia)

- INMP Serves children and adults
What Are Neuromuscular Services?

- Diagnostic evaluation
- Management of NM healthcare
  - care coordination over many years
- Education/Anticipatory guidance
- Genetic counseling
- Physical therapy
- Psychosocial support
- Community education
- Connection to research/information
Iowa NM Program

- **Clinic Sites** (~20pts/clinic)
  - Des Moines – Johnston/Child Serve (8)
  - Dubuque (1)
  - Mason City (1)
  - Quad Cities (2)
  - Sioux City (1)
  - Waterloo (2)
  - Iowa City – weekly at UIHC

- **Cost of services**
  - Insurance, Medicaid, MDA

- **About 638 outpatient visits to NM service**
  - not including inpatient consults or admissions
Number of DBMD Patients in Iowa Neuromuscular Program

6 hr drive across IA. Sites reduce drive to ~2 hrs.

105 DBMD patients in Iowa
What’s Cool About Iowa (besides the weather)

- Iowa nationally recognized as a Model of Care for DMD patients
  - Development of Care Guidelines (CDC funded)
  - Recommendations for psychosocial support & coordination of care

- Outreach – bringing services to communities
  - Overcoming lack of providers & distance to services
  - Financial barriers to accessing care

- Efficient & Accurate Diagnosis
  - Diagnostic odyssey – 2 yr delay in other US states

- Decreased morbidity & later mortality
  - Live longer (but more obesity & chronic mgt issues)

- Informed decisions – healthcare & family planning
  - Comprehensive resource for family and community
What Happens in NM Program

- **Referral to NM Clinics**
  - Intake & collection of information – talk w/ local providers
  - Anticipatory guidance – talk w/family

- **Evaluation & Diagnosis**
  - Testing, education, planning
  - Positive approach to future! (research & treatment)
  - Anticipatory guidance

- **Ongoing Management**
  - Monitoring with anticipatory guidance
  - Early intervention & prevention of complications
  - Coordination of care as complications occur
  - Consultation with other specialists
NM Program Personnel:

Each NM Clinic…

- Physician (child neurology/genetics)
- Clinical care coordinator (nurse/genetic counselor)
  - Roles: genetics, advocacy, triage, education, transitions, palliative care, coordinator across services
- Physical therapist (Center for Develop. & Disabilities)
- Social worker (Continuity of Care & Palliative Care)
  - Financial hardships, resources, psychosocial support
- Nutritionist
- MDA healthcare service coordinator

Coordination w/subspecialists
- Cardio, Pulm, Ortho, RT, GI, Endo
Coordination of Care: Neuromuscular Nurses

- **Point of contact!**
  - Direct assistance & triage
- Work closely with physicians (all services)
- Networked with community –
  - school nurses, home care, AEA, CHSC
- **Education**
  - Genetic counseling
  - Disease-related healthcare
  - Transitions
- **Advocacy:**
  - Letters of medical necessity
  - Completion of forms & documentation
  - Communication in community, school, work, etc
  - Maneuvering the healthcare systems
    - scheduling coordinated appts
- **Palliative Care**
Examples of Monitoring & Interventions

- Meet with the physical therapist
  - Teach stretching or start night splints, recommend mobility, exercise/conditioning
- Review genetic counseling issues
  - Review family history & discuss carrier risk
  - Assist in communicating genetic risk to family
  - Assess for “feelings of guilt or blame”
- Discuss steroids
  - Education materials & clarify care while on steroids
- Discuss school issues (accessibility, learning disabilities, PE class, social isolation)
- Offer support network
  - Call, email, MyChart with any question
  - Register with MDA & connect with other organizations
  - Continuity of Care Program — establish contact with social services
    - Access to financial and community based resources
- Monitoring/Interventions for complications
  - Cardiomyopathy – echo/ekg, early initiation of ACE-inhibitors, school nurse to monitor BP
  - Respiratory insufficiency – PFTs, CoughAssist
  - Loss of independence – enlist homecare agencies, AEA, VocRehab
Multidisciplinary/Interdisciplinary

- Lifetime of monitoring and interventions
  - Every 6 months for dystrophies; Annual for slower disorders
- Identify specialists who know the disease process/treatment
- Coordinate services
  (UI or local providers)
  - Cardiology
  - Pulmonary
  - Endocrinology
  - Orthopedics
  - Pathology
(pediatric & adult providers)
Are we meeting Iowa DBMD needs?

MDSTARnet Projects: Iowa Needs Assessment

Results suggest:

- Families have access to NM healthcare in Iowa
- Medical needs are adequately managed and with greater frequency & more services later in the disease
- Roles of NM doctor & care coordinators are very important
- Many Unmet needs are outside the scope of NM Program
  - Funding for DME & home modifications
  - More psychosocial support
  - More in-home help
Thanks!
– the Iowa Neuromuscular Program