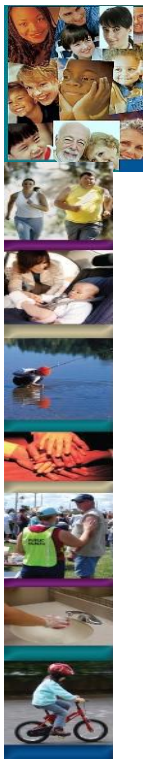
Regional Genetic Consultation Service

Contract 5880BD01 Annual Report
July 1, 2011 through June 30, 2012



Congenital & Inherited Disorders

Division of Health Promotion & Chronic Disease Prevention
Phone: 1-800-383-3826
www.idph.state.ia.us/genetics/default.asp

IDPH Iowa Department of Public Health

Regional Genetic Consultation Service:

a contract established by IDPH in the Division of Health Promotion & Chronic Disease Prevention, Contract # 5889MF01
Administrative Code, Chapter 4:641-4.5(80GA,HF2362)

Iowa Dept. of Public Health 125 YEARS

Iowa Department of Public Health

Advancing Health Through the Generations

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IDPH
Iowa Department of Public Health

In collaboration with the
Iowa Department of Public Health
&
the Department of Pediatrics
Division of Medical Genetics
University of Iowa Children's Hospital
&
Clinical Outreach Services
University of Iowa Hospitals
And Clinics

What is the Regional Genetic Consultation Service?

Iowa Administrative Code 641—4.5(80GA, HF2362) Regional genetic consultation service (RGCS). This program provides comprehensive genetic services statewide through outreach clinics.

4.5(1) ***Provision of comprehensive genetic services.*** The department shall contract with the Division of Medical Genetics within the Department of Pediatrics at the University of Iowa to provide genetic health care and education outreach services for individuals and families within Iowa.

4.5(2) ***Clinical services.*** The services provided may include, but are not limited to: diagnostic evaluations, confirmatory testing, and consultation by board-certified geneticists, genetic counseling, medical case management, and referral to appropriate agencies.

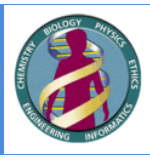
Why Does the Regional Genetic Consultation Service Exist?

Purpose: to provide genetic health care services and education for individuals and families within the State of Iowa through statewide outreach services, in order to promote health, prevent disease, reduce the incidence of congenital disorders and improve outcomes for those with congenital defects and genetic disorders.

- Over 40,000 babies are born in Iowa every year. About 1600, or approximately 4%, are born with a congenital or inherited disorder.
- In addition, there are many chronic diseases, cancers, and mental disorders which are known to have a genetic component.
- With early diagnosis and medical treatment, complications from serious conditions, such as mental retardation or even death, may be prevented, and disabilities may be eliminated or reduced.
- Genetic counseling and case management are an integral part of the genetics services which help ensure the best possible outcome for patients and families.

The RGCS program assures that genetic specialists are available to Iowans to provide medical consultation and genetic counseling.

What is Genetic Counseling?



The purpose of genetic counseling is to provide information and support to individuals and families at risk for having, or who already have, a congenital defect or genetic disorder. Genetic counseling helps the individual or family:

- To comprehend the medical facts, including the diagnosis, probable disease course, and available treatment/management;

- To understand the way heredity contributes to the disease and the risk of recurrence for themselves and other family members;
- To understand the options available to deal with the risk of recurrence;
- To identify those beliefs, values, goals and relationships affected by the risk for or presence of a hereditary disease;
- To choose the course of action that seems most appropriate to them in view of their risk, their family goals, and their ethical and religious beliefs; and
- To make the best possible adjustment to the disorder or risk of occurrence of that disorder, or both, by providing supportive counseling and making referrals to appropriate specialists, social services, and family and patient support groups.
  Thompson & Thompson, Genetics in Medicine, Edition 7

In the RGCS program, genetic counseling services are provided by a team of medical specialists which includes Board Certified Medical Geneticists, Nurse Practitioners, Genetic Counselors and Genetic Nurse Specialists.

A Patient Story

Introduction: ***Neurofibromatosis 1 (NF1)***

- A genetic disorder characterized by the tendency to develop multiple benign tumors on nerves
- Cause: a change or mutation in the NF1 gene on chromosome 17.
- One of the most prevalent genetic disorders and the most common neurocutaneous (affecting the skin and nervous systems) disorder. Affects 1 in every 3,000 births.
- Seen in all races and socioeconomic backgrounds.
- Autosomal dominant inheritance with 50-50 chance of passing NF1 on to offspring. Approximately half of those with NF1 are the first affected person in their family due a new mutation in the gene.


Jamie

Features and Characteristics:

Associated symptoms and findings may vary greatly in range and severity, even within families. The same NF1 gene mutation present in different members of the same family (ie. Brothers, sisters, grandparents, parents and children) can result in NF1 cases with widely varying degrees of severity and very different symptoms. However, common features include:

- Six or more café-au-lait spots of a specific size.
- Two or more neurofibromas of any type, or one plexiform neurofibroma.
- Multiple freckles in the axilla or groin regions.
- Distinctive bone lesions such as sphenoid wing dysplasia (absence of the bone surrounding the eye) or bowing of the tibial bone of the lower leg.
- Optic glioma (tumor of the optic nerve).
- Two or more Lisch nodules in the iris of the eye on dilated slit lamp exam.

Other features/complications may include: learning disabilities, decreased bone density, scoliosis, large head size, frequent headaches/migraines, high blood pressure, growth problems, epilepsy and cancer.

Diagnosis:
The diagnosis of Neurofibromatosis 1 can be made by a medical geneticist using very specific diagnostic criteria. Some cases may be confirmed by gene analysis which identifies a mutation in the NF1 gene.

Treatment:
There is no cure for Neurofibromatosis 1, but many of the symptoms/complications can be treated.

What to Expect:
Given the associated problems, multiple medical specialist visits may be required throughout life. Early intervention services are important to ensure that affected individuals reach their potential.

Personal Stories:
RGCS sees many Iowa patients with birth defects and inherited disorders like Neurofibromatosis 1. Through correct diagnosis, education and care coordination, these children and adults can be helped to lead healthy and productive lives.

Many of the patients seen in the RGCS program are similar to the stories shown on the website: http://www.childrenwithspecialneeds.com/

Common Types of Genetic & Congenital Disorders

Introduction to Genetic and Congenital Disorders:
A genetic disorder is a disease caused by an abnormality in an individual's DNA (deoxyribonucleic acid). DNA is the code that provides the instructions or blueprint that tells each cell in our body what it needs to know to grow and develop properly. DNA instructions are organized into segments called genes. Genes are packaged in compact units called chromosomes. Humans have 46 chromosomes and approximately 25,000 genes. Abnormalities in DNA can range from a small mutation or change in the DNA code of a single gene to the addition or subtraction of an entire chromosome or segment of a chromosome. Some genetic disorders are inherited and some are new, occurring for the first time in an individual.

Not all congenital disorders are caused by a genetic abnormality. In some cases these disorders are caused by environmental exposures during pregnancy. These exposures could include:

- Infectious agents (such as rubella, herpes and toxoplasmosis),
- Physical agents (such as high levels of radiation, high fevers and uterine abnormalities),
- Drugs and chemicals (such as prescription medications, recreational drugs, alcohol, tobacco and toxic chemicals) and;
- Maternal Factors (such as poorly controlled diabetes or PKU and malnutrition).

Still other congenital disorders, like cleft lip and palate or spina bifida, are multifactorial in nature, caused by a combination of environmental factors and one or more genes.
For more information: http://ghr.nlm.nih.gov/

Examples of Genetic/Congenital Disorders:

Angelman Syndrome	Lesch-Nyhan Syndrome
Apert Syndrome	Lissencephaly
Autism Spectrum Disorders	Marfan Syndrome
CHARGE Syndrome	Mitochondrial Disorders
Cleft lip and / or Palate	Neurofibromatosis
Cornelia de Lange Syndrome	Noonan Syndrome
Cri Du Chat Syndrome	Phenylketonuria (PKU)
Dandy-Walker Syndrome	Prader-Willi Syndrome
Deletion Syndromes	Rett Syndrome
Developmental / Growth Delay	Rubinstein-Taybi Syndrome
DiGeorge / Velocardiofacial Syndrome	Sanfilippo Syndrome
Down Syndrome	Septo-Optic Dysplasia
Familial Cancer Syndromes	Smith-Lemli-Opitz Syndrome
Fetal Alcohol Syndrome	Smith-Magenis Syndrome
Fragile X Syndrome	Spina Bifida
Ehlers Danlos Syndrome	Sturge-Weber Syndrome
Huntington's Disease	Trisomy 13 or 18
Hydrocephalus	Tuberous Sclerosis
Kabuki Syndrome	Turner Syndrome
Klinefelter Syndrome	Williams Syndrome
Laurence-Moon-Bardet-Biedl Syndrome	Von Hippel-Lindau Syndrome

Often there is no cure, but treatment and medicines can help manage some of the symptoms.

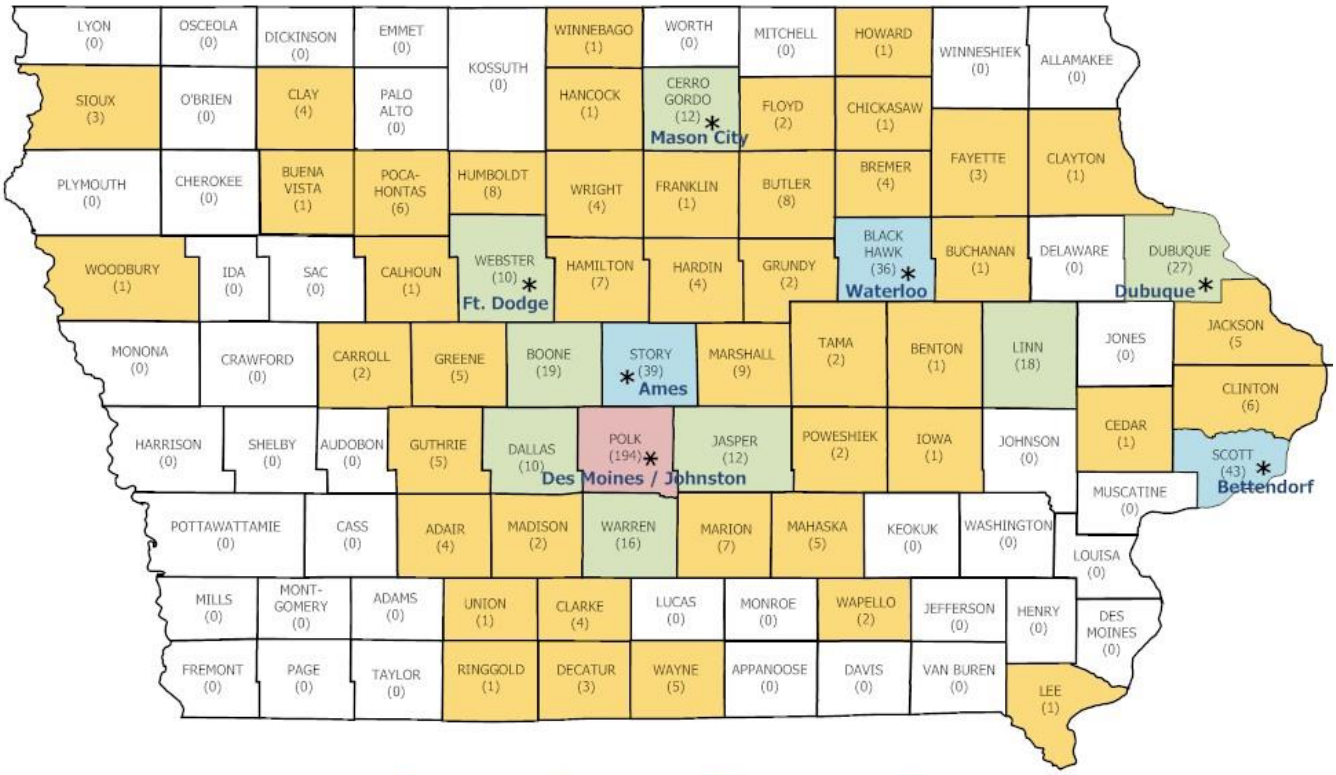
Incidence / Prevalence of Genetic & Congenital Disorders in Iowa

Genetic/Congenital Disorders	***Incidence Of Genetic / Congenital Disorders***	***Estimated # Newborns affected***
Congenital Malformations (Newborns)	~4%	1,600/yr
• Chromosome Abnormalities	~1%	400/yr
• Multifactorial/ Single gene / Environmental	~3%	1,200/yr
Other Diseases/disorders with Genetic components	***Incidence or Prevalence***	***Estimated # Affected***
Cancers – 5-10% have an inherited susceptibility	17,500 Iowans will be diagnosed with cancer/yr	875-1,750 new cancers/yr with genetic component
Chronic Diseases (heart disease, diabetes) - ~10% have a significant genetic component	>1 million Iowans suffer from at least 1 chronic disease	>100,000 individuals with these diseases have a genetic component to their disease
Mental retardation (MR) - 50% of mental retardation has a significant genetic component	~11,600 Iowa youth age 3-22 had a diagnosis of MR in 2007	~5,800 of those with MR in 2007 have a genetic component to their MR

References:
http://www.kumc.edu/gec/prof/prevalnc.html
http://www.namiiowa.com/FactsAboutMentalIllness-1.htm
http://www.netwellness.org/healthtopics/idbd/2.cfm
http://www.google.com/publicdata?ds=uspopulation&met=population&idim=state:19000&q=iowa+population
http://www.fightchronicdisease.org/pdfs/PFCD_IowaFacts.pdf
http://www.cancer-rates.info/ia
http://www.fightingautism.org

Number of RGCS Visits by Patient's County of Residence
FY 2012

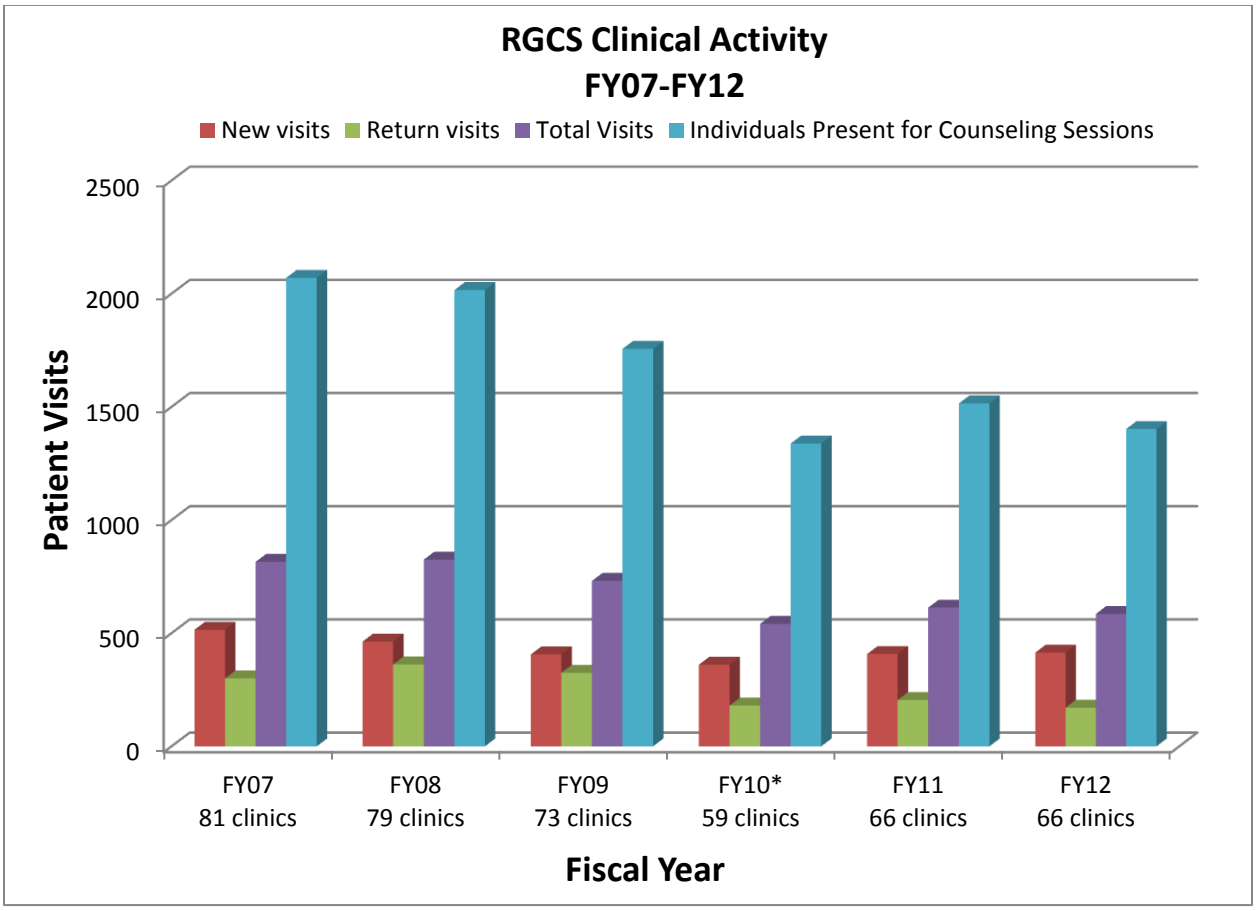
FY 2012 Iowa Outreach Genetics (RGCS) Patient Census by County



Key: ○ 0 ● < 10 ● 10-30 ● 31-100 ● > 100

Unknown Addresses - 6; Total Patients = 581;* Clinic Sites

RGCS Clinical Activity



RCGS Patient Visits	FY07 81 clinics	FY08 79 clinics	FY09 73 clinics	FY10* 59 clinics	FY11 66 clinics	FY12 66 clinics
New visits	515	463	406	361	408	414
Return visits	300	362	325	180	205	171
Total Visits	815	825	731	541	613	585
Individuals Present for Counseling Sessions	2070	2016	1756	1338	1515	1402

* At the end of FY09 two physicians resigned, leaving two physicians to staff all of the genetics clinics for RGCS and UIHC. The two physicians that were subsequently hired began doing RGCS clinics in November 2009 and January 2010.

RGCS Patient Population by Age and Gender

	2006*		2007*		2008*		FY 2010		FY 2011		FY 2012		% Gender by Age (6 year average)		
AGE	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	
1-364 dys	61	65	61	51	55	56	39	34	29	28	43	34	7.60%	7.08%	
1-4 yrs	91	102	119	123	79	93	71	79	76	96	83	58	13.70%	14.55%	
6 YEAR TOTAL UNDER 5 YEARS of AGE															**42.94%**
5-9 yrs	49	92	59	71	65	86	42	58	59	80	59	57	8.79%	11.72%	
10-14 yrs	44	55	44	48	35	39	30	34	36	44	45	51	6.18%	7.16%	
15-19 yrs	22	21	23	15	18	16	20	29	30	30	30	18	3.78%	3.41%	
6 YEAR TOTAL 5-19 YEARS of AGE															**39.86%**
20-29 yrs	29	13	25	11	25	7	27	7	25	12	23	14	4.07%	1.69%	
30-39 yrs	23	13	23	14	17	4	15	8	30	10	23	16	3.46%	3.30%	
40-49 yrs	5	3	8	11	11	3	12	5	10	4	11	7	1.51%	0.87%	
50-59 yrs	7	4	9	4	5	4	11	5	6	1	6	1	1.16%	0.50%	
60-69 yrs	5	0	3	1	1	3	4	4	2	0	3	1	0.48%	0.24%	
70 &older	1	3	1	1	1	0	2	1	1	0	1	1	0.18%	0.16%	
6 YEAR TOTAL OVER 20 YEARS of AGE															**17.61%**
Totals	**337**	**371**	**375**	**350**	**312**	**311**	**273**	**264**	**304**	**305**	**327**	**258**	**1928**	**1859**	**100.41%**

*Denotes Calendar Years

Services Provided by the Regional Genetic Consultation Services Per Contract

The RGCS contract for FY 2012 required a minimum of 35 clinics be held. Expectations and services provided included:

Physician Evaluation and Medical Management

- **Consultation by board-certified geneticists**
- **Diagnostic Evaluation**
  - Detailed examinations
  - Review of family history and medical records
  - Diagnostic and confirmatory testing
- **Management of health care concerns**
  - Medical management to slow progression of disease, control pain, treat symptoms
  - Ongoing monitoring
  - Referrals to other specialists, as needed

Genetic Counseling, Care Coordination, Education and Advocacy

- **Patient and Family Education**
  - Written and verbal information specific to disease process, treatment & management
  - Genetic counseling for patient and families including information regarding recurrence risks
  - Anticipatory guidance regarding prognosis and level of disability
    - Information about advance directives & living wills, as appropriate
    - Education of school personnel, employers, childcare providers and others
    - Updates on research for patients, families and healthcare providers
- **Patient & Family Support Services**
  - Phone triage and assistance with daily management of emotional, social and physical aspects of the disorder.
  - Advocacy in communicating with educators, employers, health insurers and others.
  - Assistance in identifying social services & financial services
  - Referrals to educational resources, home health care, respite and hospice services
  - Referrals to patient and family support groups
  - Access to research opportunities, as desired

Medical Geneticist Consultation to Iowa Physicians available 24 hours per day, 365 days per year.

Educational presentations and activities

- Provide educational presentations
- Provide educational opportunities for medical students and professionals

In addition, the RGCS staff is to:

- Participate in the activities of the Center for Congenital and Inherited Disorders (CCID) Advisory Committee, providing assistance and technical support to the IDPH.

- Coordinate and integrate services with other programs serving similar purposes and populations.
- Utilize a sliding fee scale based on federally established percent of poverty guidelines for specialty genetics provider services for patients attending the RGCS clinics (see next section regarding program changes).
- Assure that payments received from services based on the sliding fee scale or from third party payers are used only to support the activities of the RGCS (see next section regarding program changes).

Evaluation of RGCS FY 2012
Has RGCS Met Contract Objectives?

Meeting Contract Objectives:

- In FY 2012 the RGCS program conducted 66 clinics in 8 Iowa communities, providing 585 clinic visits for patients and/or families. Over 1,400 patients, family members and caregivers participated in these visits. The clinics were staffed by geneticists, nurse practitioners and genetic/nurse counselors who provided genetic evaluation and medical management, genetic counseling, care coordination, education, support and advocacy. The majority of the clinics (41 of the 66) were held in the Des Moines and Ames sites in order to help increase accessibility for individuals living on the west side of Iowa.
- The RGCS staff is actively involved in education of a variety of health care professionals and students on a routine basis. Many hours are spent with genetics and pathology fellows; medical students; graduate nursing students; residents from family practice, pediatrics, pathology and dentistry; genetic counseling interns; cytogenetic staff; and high school and undergraduate college students, both in the clinical and the academic setting. All staff are involved in the Medical Genetics class and/or small group sessions that is held for the 1st year medical students at the University of Iowa. They also present regularly in the Genetics Journal Club which meets weekly for interested staff members.
- RGCS staff are also available for presentations on a variety of genetics related topics. Presentations have been made this past year to physician groups, dietician interns, Iowa Nurse Practitioners and families with Neurofibromatosis. Members of the RGCS team have also done poster presentations at national genetics meetings including: the American College of Medical Genetics and the American Society of Human Genetics.
- RGCS Staff have participated in CCID meetings and activities throughout FY 2012.
- RGCS staff collaborates with Child Health Specialty Clinics, Early ACCESS and the statewide Area Education Agencies, Newborn Screening and other programs to coordinate and integrate services with other programs serving similar purposes and populations.
- All patients/families seen at each RGCS clinic through March 2012*** were offered the opportunity to apply for the sliding fee scale to determine if they are eligible for a fee reduction in the physician charge for their visit.
- Payments received from the receipts of fee for service through March 2012*** were used for RGCS program expenses only.

Beginning April 1, 2012 the oversight of the organization and structure of the RGCS program was transitioned to the Clinical Outreach Services of the University of Iowa Hospitals and Clinics. Clinical Outreach began providing the following services to the RGCS program: clinic scheduling; clinic site negotiations, contract development and payment of site rental fees; transportation to and from clinic for clinic staff; medical personnel for onsite clinic registration; salary support for physicians' and nurse practitioners' for the hours spent driving to and from clinic and staffing each clinic; clinic supplies and distribution of clinic summary letters.

Beginning with the April RGCS clinics, all moneys received from fee for service for patient visits has been directed to the Clinical Outreach Service to pay for the above services. The sliding fee scale that had previously been offered for patients/families was discontinued at that same time. The Iowa Administrative Rules (641—4.5(3) Patient fees) are currently under revision to in order to reflect these changes.

The money that is received from the Iowa Department of Public Health contract supports the salaries of the genetic/nurse counselors in the RGCS program who provide genetic counseling and case management/care coordination services; program administrative management and supplies including patient education materials.

National Performance Measures / Priorities Outlined in Iowa's Family Health Plan that RGCS Participated in During FY 2012

Assure families of children with special health care needs age 0-18 years are partners in decision making at all levels and are satisfied with the services they receive.

National Measure #2

A central part of the services provided by the RGCS staff is the education and counseling of families/patients regarding their specific disease process, recurrence risks in future pregnancies, recommended treatment/management and current research with an ultimate goal of empowering them to make choices regarding their health care that best meet their individual/family needs. Referrals to support groups, the Parent Consultant Network through Child Health Specialty Clinics and other medical resources also help to assure family involvement/decision making in meeting the child's health care needs. To assess satisfaction with genetics services, families are provided with an opportunity to complete a satisfaction survey following their clinic visit. This information is used to improve services whenever possible.

Assure children with special health care needs age 0 to 18 receive coordinated, on-going, comprehensive care within a medical home. **National Measure #3**

Many of the patients seen in the RGCS clinic have very complex health care needs. The genetics staff strives to provide a comprehensive assessment of the individual's medical,

social and educational needs. Although only a few patients actually have a medical home, clinic summary and results letters are used to communicate the genetics assessment, recommendations/plan of care and results of evaluations to the primary care physician/medical home/referring physician to assist with coordination of services. Whenever possible/available, local resources are utilized to meet the patient's special needs.

Assure families of children with special health care needs age 0 to 18 have adequate private and/or public health insurance to pay for the services they need. **National Measure #4**

As part of its role with families and patients, the RGCS staff assists families/parents to identify social services and financial resources to meet their health care needs, aiding in the application process if needed. Staff advocates for patients by communicating with health insurers regarding the importance of appropriate diagnostic testing, management and treatment for specific (often rare) genetic disorders, providing educational resources as needed. RGCS staff also participate in the Center for Congenital and Inherited Disorders Advisory Committee where there is an opportunity to have dialogue with members of the Iowa Insurance Commission regarding health care needs of children/patients with complex health conditions..

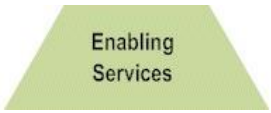
Assure families of children with special health care needs age 0 to 18 have access to community-based services that are organized for easy use. **National Measure #5**

The RGCS program continues to provide outreach genetics services throughout eastern and central Iowa in an attempt to improve access for these unique services for Iowans. Clinic sites utilized are generally health care facilities that are easily accessible and in close proximity to a variety of other health care services. As previously mentioned, whenever possible/available, local/community resources are utilized to meet the patient's needs.

Assist youth with special health care needs to receive services necessary for successful transition to all aspects of adult life, including health care, work, and independence. **National Measure #6**

The Regional Genetic Consultation Service provides care to individuals of all ages. Because of this the staff is acutely aware of the need to help transition youth with complex health care needs to adult programs and services as they reach adulthood. Staff serve as advocates for patients and assist with location of resources and referrals for medical, social and educational services as needed.

RGCS Alignment with MCH Block Funding

	**DIRECT CARE** • Diagnosis • Testing • Counseling • Gap-filling
	**ENABLING SERVICES** • Strong collaboration with AEA & Early ACCESS, Continuity of Care, Ill & Handicapped Waiver, CHSC, Transportation Services, Translation and family support services • Care Coordination / Community Planning
	**POPULATION BASED SERVICES** • Provide feedback to the Iowa Newborn Screening Program about future screening • Participation in the Iowa Birth Defects Registry for Congenital and Inherited Disorders – conducts surveillance / population based monitoring for children born in Iowa with congenital and inherited disorders
	**INFRASTRUCTURE BUILDING SERVICES** • Participation in development of National Guidelines, Policy Development, Quality Assurance Activities • Agency Coordination: Receives and gives referrals to Area Education Agency, Early Access, Ill and Handicapped Waiver, Department of Human Services, Shriner's, Down Syndrome Clinic and many others • Training: Local and Future healthcare providers (MD, NP, PT, RN) • Applied research: provides patients and clinicians access to research for patients

RGCS Director Statements

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Medical Genetics started at the beginning of the 20th century when it was recognized that the occurrence of some human diseases in families could be explained by Mendel's principles. During the past several decades, Medical Genetics has grown into a medical specialty concerned with the diagnosis and management of many disorders, including both rare and common diseases. It is now recognized that nearly all diseases have a genetic component. Medical Genetics focuses not solely on individual patients, but on the entire family.

The obtaining of a comprehensive family history is an important first step in the practice of good medicine as it can lead to diagnosis, prognosis, and assessment of recurrence risk in family members. This information, in turn, plays a key role in the proper counseling, management and disease prevention for patients and their families. The Iowa Regional Genetic Consultation Service (RGCS) began nearly thirty-five years ago with the goal of providing Iowa patients and families with proper medical treatment and information utilizing the most current genetic information and resources.

In the past several years, the Human Genome Project, an international effort to determine the complete sequence of the totality of DNA containing all human genetic information (the human genome), has allowed the identification of all genes and is facilitating the identification of genetic variation which contributes to disease. Along with other advances including information management and biological technologies, the Human Genome Project is revolutionizing the practice of medicine by improving diagnosis, disease prevention and treatment based on genetic information. The opportunities afforded by the Human Genome Project and other advances in genetics are being and will be utilized by the RGCS program for the betterment of the health of Iowans in a number of ways including the following:

Diagnosis:
Individuals with birth defects are undergoing very high-resolution genome testing to identify genetic duplications and deletions causing congenital malformations and other disorders. The resolution of such testing using DNA microarray technology (DNA chips) makes it possible to identify smaller and smaller abnormalities.

The identification of human genes and the mutations associated with hundreds of genetic diseases are making it possible to make disease diagnoses based on genetic sequences, thus differentiating between highly hereditable diseases and diseases with low heritability.

Disease Prevention:
Genetic testing is making it possible to detect individuals at risk for disease even prior to onset of symptoms. In some cases, interventions are available to lower the risk of developing the disease, or at a minimum lead to early identification and management of disease symptoms.

Treatment:
In some cases, genetic analysis allows for selection of the most effective treatment. For example, genetic analysis of a tumor sample from a cancer patient can aid in the selection of the most effective chemotherapy for the patient, as well as avoiding adverse reactions to a chemotherapeutic agent in a particular patient.

While the above examples are currently possible for some disorders, the future holds the extension of diagnostic, prevention and treatment modalities to countless additional diseases and individuals. In the near future, more sensitive and affordable genetic tests, along with novel therapies will continue to expand the need for genetic services. The RGCS program will continue to be key component to the delivery of genetic services to patients and families within the State of Iowa.

Barriers, Challenges and Additional Facts

The RGCS has held 2,602 clinics and more than 25,180 patient/family visits over the past 36 years. As in previous years, the new referrals to genetics (for RGCS and UIHC clinics) continue to exceed the clinic and staff capacity. At the end of FY 2012 one of the RGCS/UI genetics physicians resigned. To date this position has not been filled and the recruitment process is just beginning. Finding adequate numbers of qualified genetics personnel is always a challenge.

The typical wait time for a genetics appointment for a “non-critical” patient is often 4-6 months. As a result, the backlog of patients awaiting appointments, particularly those awaiting follow-up, continues to be a major issue of concern. The genetics staff is attempting to deal with this by: timely review and assessment of patient acuity and prioritizing patient’s/physician’s requests for clinic appointments; increasing the number of patient appointments per clinic day; overbooking appointments at the University on non-clinic days when needed, and providing medical recommendations for local providers to begin the evaluation process prior to the genetics appointment.

Transportation can be a significant barrier for some families, particularly for those with limited resources who live a distance from the clinic sites. Resources, such as TMS (Non-Emergency Medical Transportation service), have often been sorely inadequate and frequently obstructive for families Since we are currently holding no clinics on the western part of the state, families from that area are being referred to resources in surrounding states that are closer to their residence.

Insurance issues continue to be a major challenge for staff and families. Many procedures such as MRIs and echocardiograms require prior approval. Often genetic laboratory testing is

expensive, beyond what the typical family can afford. Preauthorization may require significant amounts of genetics staff time to complete the necessary paperwork and/or telephone conversations with insurance personnel. This process is not only time consuming, but can significantly prolong the evaluation of the patient.

Use of Sliding Fee Scale

RGCS Sliding Fee Scale Data						
67.2% of patients qualified for reduction in fee						
FY12 - July 11 - June 12						
	# of Clinics	**0%**	**25%**	**50%**	**75%**	**100%***
July	6	15	0	1	6	32
Aug	5	13	5	0	1	31
Sept	4	7	0	2	3	20
Oct	7	17	1	2	4	39
Nov	6	15	4	3	0	31
Dec	4	14	0	1	0	17
Jan	6	18	2	0	0	19
Feb	5	22	3	0	1	24
Mar	6	18	1	2	1	29
Apr	8					
May	6					
Jun	5					
TOTAL	66	139	16	11	16	242
%		32.8%	3.8%	2.6%	3.8%	57.1%
*78.5% of the patients that qualify for 100% reduction in fee are covered by Medicaid or Hawk-I						

The sliding fee scale was used for patients seen in clinics from July 1, 2011 through March 31, 2012.