

# Regional Genetic Consultation Service



Contract 5880BD01 Annual Report  
July 1, 2010 through June 30, 2011





## **Congenital & Inherited Disorders**

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



### **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 Department of Public Health**

*Advancing Health Through the Generations*

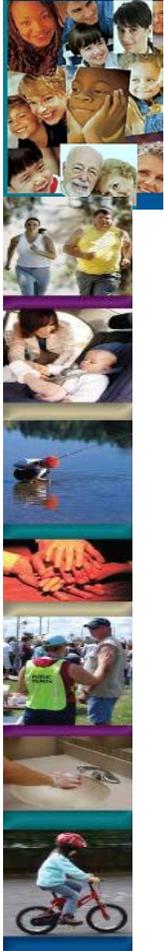
Terry Branstad     Kimberly Reynolds     Mariannette Miller-Meeks  
Governor             Lt. Governor             Director

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In collaboration with the  
Iowa Department of Public Health  
&  
the Department of Pediatrics  
Division of Medical Genetics  
University of Iowa Children's  
Hospital

## 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, 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 consultation, testing and recommended evaluations often cost hundreds to thousands of dollars and are cost prohibitive for most families.

The RGCS program ensures that genetic specialists are available to provide medical consultation and genetic counseling, and assures access to all Iowans with the use of a sliding fee scale for physician charges which is a condition of this state contract.

## 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 and Genetic Counselors and Genetic Nurse Specialists.

## A Patient Story

### **Introduction:** *Trisomy 9 Mosaic Syndrome*

- Birth defects that occur in early fetal development.
- Cause: an extra copy of chromosome 9 in some cells of the body
- Very rare, occurring in both males and females,
- Has been seen in all races and socioeconomic backgrounds.
- Typically sporadic (no other affected members in the family).



### **Features and Characteristics:**

The name “Trisomy” means three (tri) copies of a chromosome (somy). Unlike most individuals, people that have any form of Trisomy are born with a whole or partial third copy of a chromosome, instead of the expected two. For example, a child that has a third copy of the 21<sup>st</sup> chromosome, rather than just 2 copies, has a common disorder called Down’s syndrome. With Trisomy 9 Mosaic Syndrome the entire 9<sup>th</sup> chromosome is present in some cells of the body. The term “mosaic” indicates that some cells of the body contain the extra chromosome 9, while other cells have the normal chromosome pair.

Associated symptoms and findings may vary greatly in range and severity, depending on the percentage of cells with the extra chromosome and their location within the body. However, common features include:

- Growth deficiency before birth (intrauterine growth retardation).
- Mental retardation.
- Structural malformations of the heart that are present at birth (congenital heart defects).

- Distinctive abnormalities of the face and skull, such as a sloping forehead, a bulbous nose, short eyelid folds (palpebral fissures), deep set eyes, and low-set, malformed ears
- Other features may include: Neuromuscular problems such as low muscle tone, apnea, and seizures; Genital abnormalities; and Kidney/renal abnormalities.

**Diagnosis:**

The diagnosis of Trisomy 9 Mosaic Syndrome should be made by a medical geneticist and is confirmed by chromosome analysis which identifies the extra copy of chromosome 9.

**Treatment:**

There is no cure for Trisomy 9 Mosaic Syndrome, but many of the symptoms can be treated.

**What to Expect:**

Given the associated problems, multiple hospitalizations and 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 Trisomy 9 Mosaic Syndrome. Through correct diagnosis, education and care coordination, these special 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

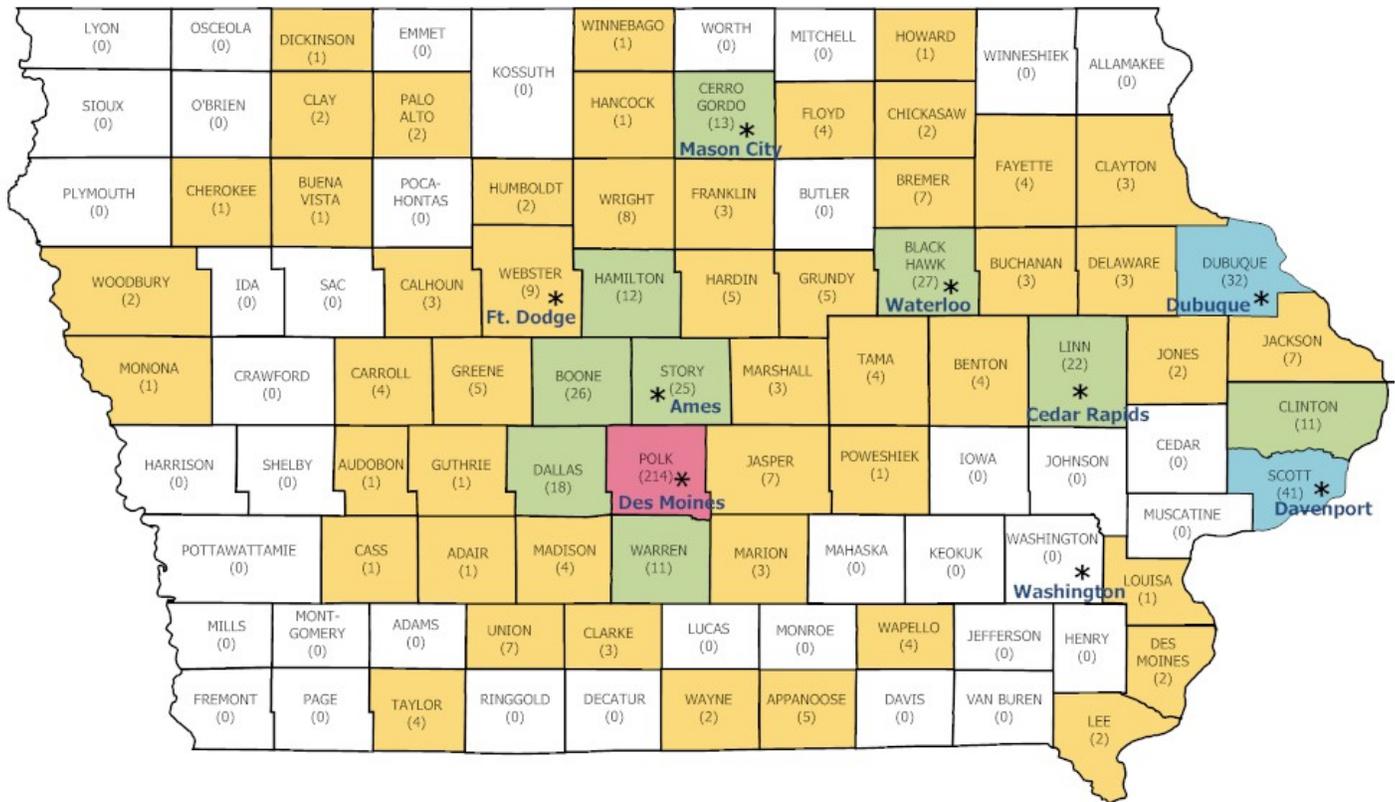
<b>Genetic/Congenital Disorders</b>	<b>Incidence Of Genetic / Congenital Disorders</b>	<b>Estimated # Newborns affected</b>
Congenital Malformations (Newborns)	~4%	1,600/yr
• Chromosome Abnormalities	~1%	400/yr
• Multifactorial/ Single gene / Environmental	~3%	1,200/yr
<b>Other Diseases/disorders with Genetic components</b>	<b>Incidence or Prevalence</b>	<b>Estimated # Affected</b>
Cancers – 5-10% have an inherited susceptibility	16,000 Iowans are diagnosed with cancer/yr	800-1,600 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&idm=state:19000&q=iowa+population>  
[http://www.fightchronicdisease.org/pdfs/PFCD\\_IowaFacts.pdf](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 2011

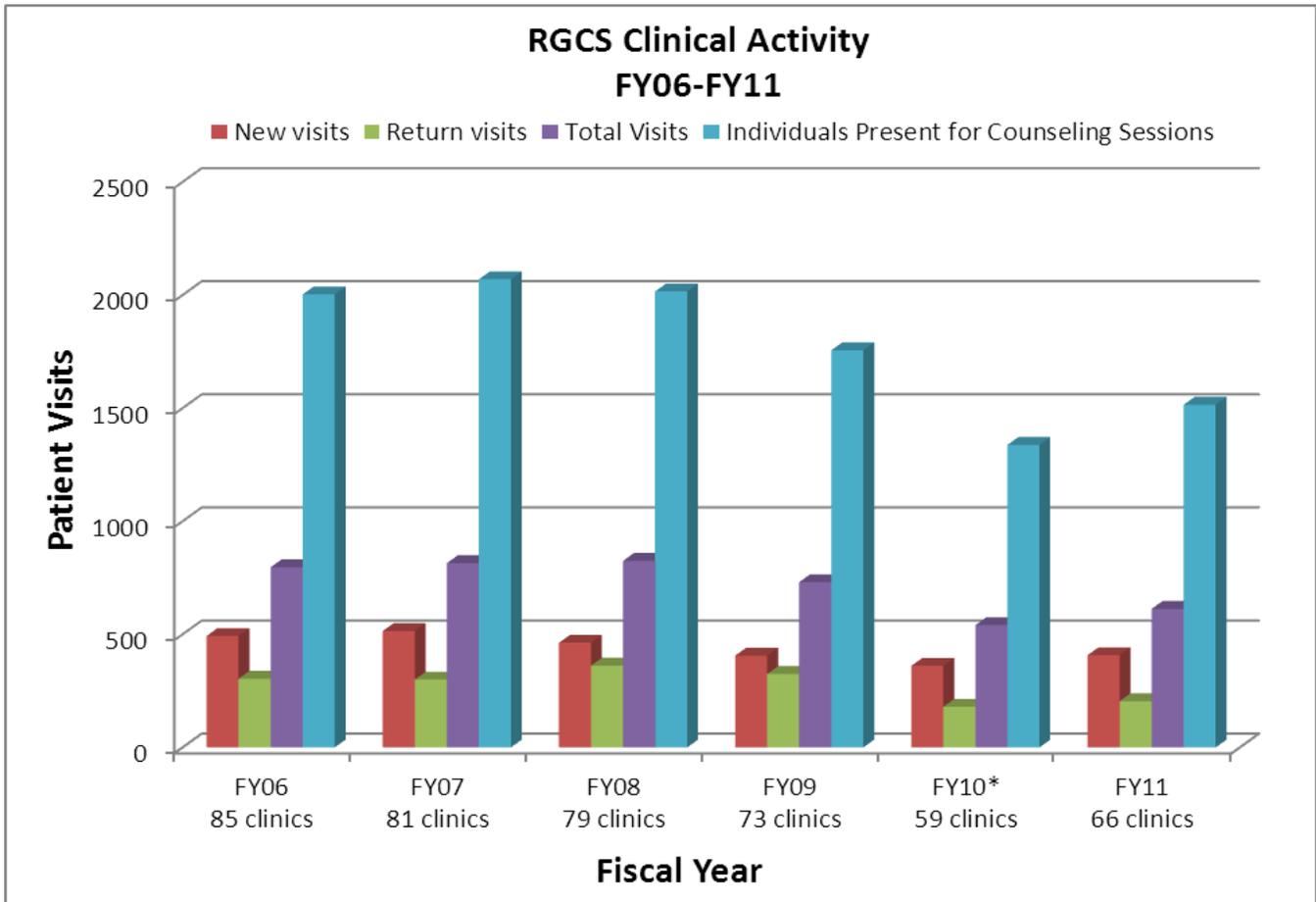
## FY 2011 Iowa Regional Genetics Visit Census by County



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

Unknown Addresses - 9; Total Visits = 613; \* Clinic Sites

## RGCS Clinical Activity



RGCS Patient Visits	FY06 85 clinics	FY07 81 clinics	FY08 79 clinics	FY09 73 clinics	FY10* 59 clinics	FY11 66 clinics
<b>New visits</b>	493	515	463	406	361	408
<b>Return visits</b>	304	300	362	325	180	205
<b>Total Visits</b>	797	815	825	731	541	613
<b>Individuals Present for Counseling Sessions</b>	2003	2070	2016	1756	1338	1515

\* 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

AGE	2005*		2006*		2007*		2008*		FY 2010		FY 2011		% Gender by Age (6 year average)		
	Female	Male	Female	Male											
<b>1-364 dys</b>	58	67	61	65	61	51	55	56	39	34	29	28	7.76%	7.71%	
<b>1-4 yrs</b>	71	118	91	102	119	123	79	93	71	79	76	96	12.99%	15.65%	
<b>6 YEAR TOTAL UNDER 5 YEARS of AGE</b>														<b>44.11%</b>	
<b>5-9 yrs</b>	65	77	49	92	59	71	65	86	42	58	59	80	8.68%	11.88%	
<b>10-14 yrs</b>	37	46	44	55	44	48	35	39	30	34	36	44	5.79%	6.81%	
<b>15-19 yrs</b>	21	16	22	21	23	15	18	16	20	29	30	30	3.43%	3.25%	
<b>6 YEAR TOTAL 5 YEARS TO UNDER 20 YEARS of AGE</b>														<b>39.86%</b>	
<b>20-29 yrs</b>	32	14	29	13	25	11	25	7	27	7	25	12	4.18%	1.64%	
<b>30-39 yrs</b>	20	9	23	13	23	14	17	4	15	8	30	10	3.28%	1.49%	
<b>40-49 yrs</b>	20	5	5	3	8	11	11	3	12	5	10	4	1.69%	0.79%	
<b>50-59 yrs</b>	12	4	7	4	9	4	5	4	11	5	6	1	1.28%	0.54%	
<b>60-69 yrs</b>	2	3	5	0	3	1	1	3	4	4	2	0	0.44%	0.28%	
<b>70 &amp; older</b>	4	1	1	3	1	1	1	0	2	1	1	0	0.26%	0.15%	
<b>6 YEAR TOTAL OVER 20 YEARS of AGE</b>														<b>16.01%</b>	
<b>Totals</b>	<b>342</b>	<b>360</b>	<b>337</b>	<b>371</b>	<b>375</b>	<b>350</b>	<b>312</b>	<b>311</b>	<b>273</b>	<b>264</b>	<b>304</b>	<b>305</b>	<b>1943</b>	<b>1961</b>	<b>99.98%</b>

\*Denotes Calendar Years

# Services Provided by the Regional Genetic Consultation Services Per Contract

The RGCS contract for FY 2011 required a minimum of 50 clinics be held. Expectations 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.*

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.
- 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.

## Evaluation of RGCS FY 2011 Has RGCS Met Contract Objectives?

### Meeting Contract Objectives:

- In FY 2011 the RGCS program conducted 66 clinics in 9 Iowa communities, providing 613 clinic visits for patients and/or families. Over 1,500 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.
- RGCS Staff have been active participants in CCID meetings and activities throughout FY 2011.
- 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 are 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 are used for RGCS program expenses only.

## National Performance Measures / Priorities Outlined in Iowa's Family Health Plan that RGCS Participated in During FY 2011

Assure families of children with special health care needs are partners at all levels of decision making and are satisfied with services received.

### **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, 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 coordinated on-going comprehensive care within a medical home for children with special health care needs.

### **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, a

clinic summary letter is used to communicate the genetics assessment and recommendations to the primary care physician/medical home to assist with coordination of services. Whenever possible/available, local resources are utilized to meet the patient's needs.

Assure families of children with special health care needs have adequate private and/or public health insurance. **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 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 assist with location of resources and referrals for medical, social and educational services as needed.

# RGCS Alignment with MCH Block Funding

 <p>Direct Care</p>	<p><b>DIRECT CARE</b></p> <ul style="list-style-type: none"> <li>• Diagnosis</li> <li>• Testing</li> <li>• Counseling</li> <li>• Gap-filling</li> </ul>
 <p>Enabling Services</p>	<p><b>ENABLING SERVICES</b></p> <ul style="list-style-type: none"> <li>• Strong collaboration with AEA &amp; Early ACCESS, Continuity of Care, III &amp; Handicapped Waiver, CHSC, Transportation, Translation and family support services</li> <li>• Sliding fee schedule for MD fees</li> <li>• Care Coordination / Community Planning</li> </ul>
 <p>Population Based Services</p>	<p><b>POPULATION BASED SERVICES</b></p> <ul style="list-style-type: none"> <li>• Provide feedback to the Iowa Newborn Screening Program about future screening</li> <li>• 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</li> </ul>
 <p>Infrastructure Building Services</p>	<p><b>INFRASTRUCTURE BUILDING SERVICES</b></p> <ul style="list-style-type: none"> <li>• Participation in development of National Guidelines, Policy Development, Quality Assurance Activities</li> <li>• Agency Coordination: Receives and gives referrals to Area Education Agency, Early Access, III and Handicapped Waiver, Department of Human Services, Shriner's, Down Syndrome Clinic and many others</li> <li>• Training: Local and Future healthcare providers (MD, NP, PT, RN)</li> <li>• Applied research: provides patients and clinicians access to research for patients</li> </ul>

## RGCS Director Statements

Val C. Sheffield, MD, PhD  
Professor of Pediatrics  
Medical Director, Division of Medical Genetics  
Howard Hughes Medical Institute Investigator

Pamela Trapane, MD  
Clinical Associate Professor of Pediatrics  
Clinical Director, Division of Medical Genetics

Medical Genetics started at the beginning of the 20<sup>th</sup> 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 heritable 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.

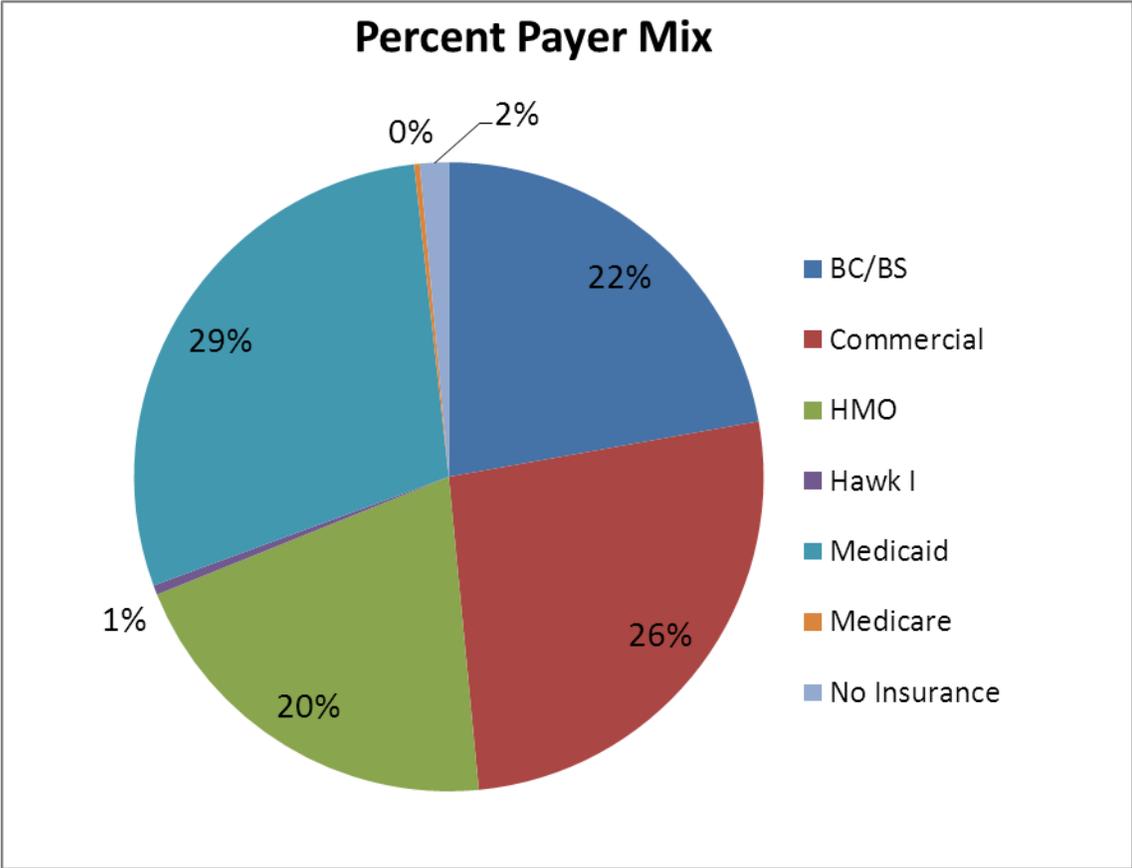
## 2011 Program Budget Snapshot

	<u>Contract</u>	<u>MD Fees</u>
<b>Program Income for FY10 Expenses:</b>	\$ 470,534	\$ 93,624
• Personnel	426,223	44,539
• General Expenses/Travel to Clinic/Reduction in Charges	44,311	49,085
<b>TOTAL DIFFERENCE</b>	<b>-0-</b>	<b>-0-</b>

The RGCS program runs on two different accounts. One is the RGCS Contract and the other is the fees generated from seeing patients in the program. For FY 2011, the amount of the RGCS contract was reduced by \$17,684 from the previous fiscal year. For this fiscal year, we had a philosophical shift in how contract dollars were spent. The primary expense on the contract is for personnel who provide genetic care coordination and counseling to patients seen in the program; as well as providing genetic care coordination and counseling to patients and health care providers throughout Iowa. A small portion of salary expense for the program's clinical director and the medical consultants for the program (all MD geneticists) are also paid from the contract. The medical consultants provide physical examinations, genetic evaluations, and genetic test interpretations for patients seen in the program. They also provide a genetic consultative service to physicians and allied health care providers across the state 24/7/365. The rest of the expenses on the contract include fees for interpreters for non-English speaking patients; medical equipment and supplies; office supplies, telecommunication costs, and travel costs to and from clinic.

The MD Fee portion of the program shows a net income of \$93,624. Gross income was \$176,123. The different of \$82,499 is indicative of the reduction of fees due to contractual and courtesy allowances (insurance company reductions); reductions in charges from applying the sliding fee scale, and bad debt. Expenses include personnel (physician and administrative staff); continuing education costs, and other miscellaneous expenses.

# Payer Mix for RGCS



## Use of Sliding Fee Scale

RGCS Sliding Fee Scale Data						
74.2% of patients qualified for reduction in fee						
FY10 - July 10 - June 11						
	# of Clinics	0%	25%	50%	75%	100%*
July	5	14	2	0	1	39
Aug	6	19	1	1	1	34
Sept	6	8	2	0	1	40
Oct	6	12	0	2	0	42
Nov	4	6	0	2	0	29
Dec	5	16	1	1	1	33
Jan	5	11	4	3	0	25
Feb	7	17	2	5	4	38
Mar	3	4	0	1	2	18
Apr	8	23	0	2	0	52
May	6	15	1	0	0	34
Jun	5	14	2	2	3	23
<b>TOTAL</b>	66	159	15	19	13	407
<b>%</b>		25.9%	2.4%	3.1%	2.1%	66.4%
*82.6% of the patients that qualify for 100% reduction in fee are covered by Medicaid or Hawk-I						

Use of the sliding fee schedule allows access of care to patients who might not otherwise be able to afford the care.

### Additional “Facts”

RGCS has held 2,536 clinics and more than 24,600 patient/family visits over the past 35 years. **As in previous years, the new referrals to genetics each month in FY 11 (for RGCS and UIHC clinics) continued to exceed the clinic and staff capacity. As a result, the backlog of patients awaiting appointments, particularly those awaiting follow-up, continues to be an issue of concern. The genetics staff attempts to deal with this by reviewing and prioritizing patient’s/physician’s requests for clinic appointments, assessing acuity, providing medical recommendations for local providers and overbooking appointments when needed.**

Currently the RGCS program cannot meet the demand or desire for genetic care. Advances in this field are expanding exponentially and new treatments are becoming available. It is also clear, with the growing crisis of chronic disease in Iowa and our increasing understanding of the role of genetics in these conditions; this program has the potential to be an integral part of the solution by providing increased services to individuals and families with these chronic diseases.