

# **International Study of Familial Glioma (Gliogene) Developing a Successful Consortium**



**2<sup>nd</sup> NCI Rare Cancers  
Meeting**

**May 9<sup>th</sup>, 2007**

**Melissa Bondy, Ph.D.  
M.D. Anderson  
Cancer Center**



**THE UNIVERSITY OF TEXAS  
MD ANDERSON  
CANCER CENTER**  
*Making Cancer History®*

# History of Gliogene

- Brain Tumor Epidemiology Consortium (BTEC) formed in February 2003 (1<sup>st</sup> meeting at NCI)
- Research groups and leadership established
- Family studies group chaired by Melissa Bondy and Beatrice Malmer



# Rationale to Develop a Family Study?

- New insights of genes important to glioma development
- Genes could provide insights to sporadic gliomas
- Disadvantage: Rare
- Consortium needed to study rare cancers

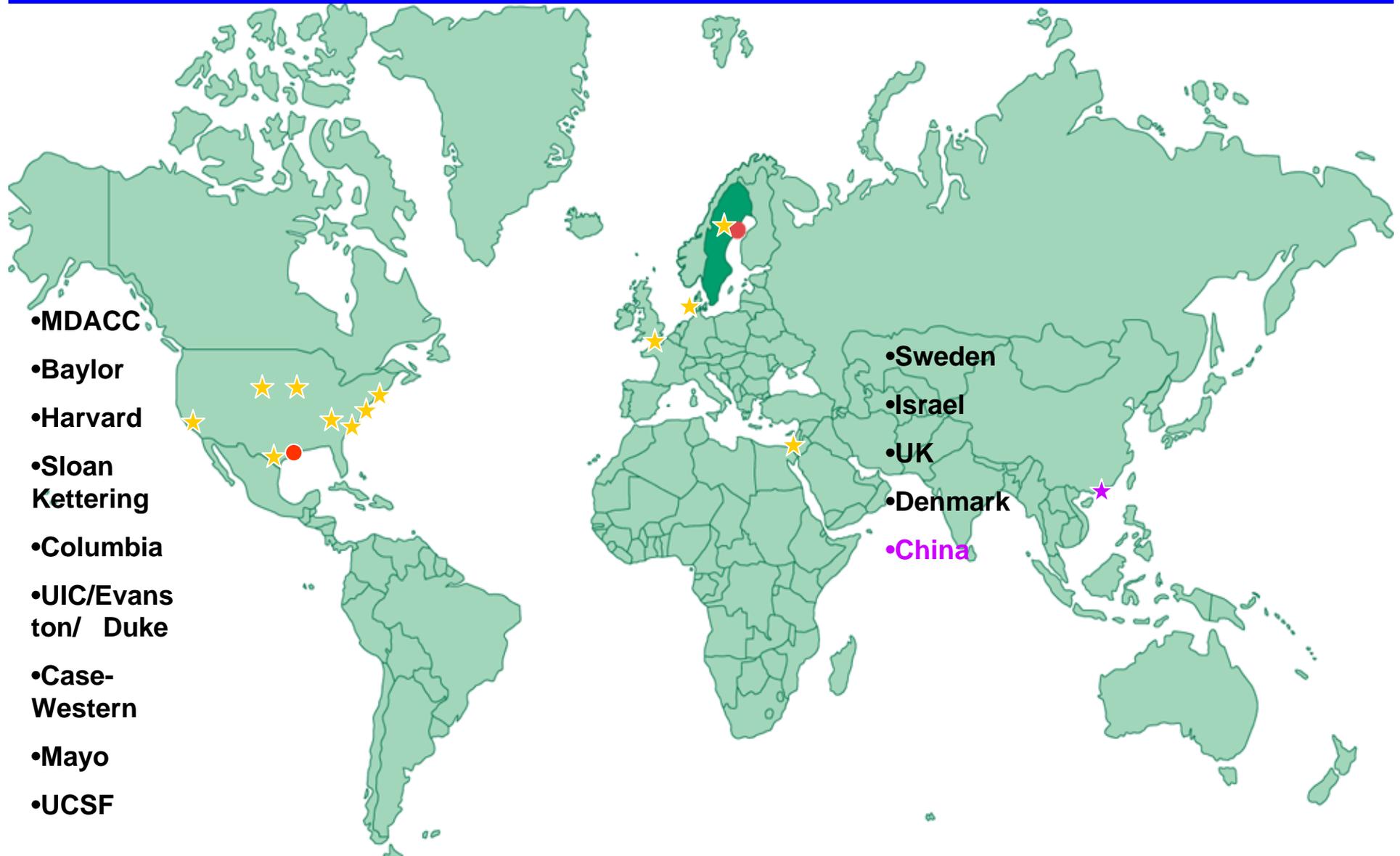


# History of Gliogene

- Grant initially submitted in October 2005
- Funded after 2<sup>nd</sup> submission in 9/2006 with a 29% cut
- Received supplemental funding (American Brain Tumor Association, National Brain Tumor Foundation), and in-kind contributions from Tug McGraw Foundation
- First investigator meeting held in Houston in December 2006



# Glioma International Consortium – GLIOGENE



# Structure of GLIOGENE CONSORTIUM

**Steering Committee**  
(PI from each site)

## Advisory Committee

Ake Borg (Sweden)	Howard Fine (NCI)
Stephen Channock (NCI)	Carol Krutchko (CBTRUS)
Doug Easton (UK)	Gloria Petersen (Mayo)
Robert Elston (Case-Western)	Neil Risch (Stanford)

## Data collection sites

- **U.S.**
- BWH (Claus)
- Case-Western (Barnholtz-Sloan) –
- Columbia University (Lai)
- Duke/UIC (Davis)
- Mayo (Jenkins/Yang)
- MDACC (Bondy)
- Memorial Sloan Kettering (Bernstein/Olsen)
- **Europe/Israel**
- Denmark (Johannsen)
- Israel (Sedetzki)
- Sweden (Malmer)
- UK (Houlston)

## Genotyping

**U.S.**

Baylor (Lau)

**Europe**

Sutton, England (Houlston)

## Data Management & Statistics

**U.S.** (Shete, Amos, Barnholtz-Sloan)

**Sweden** (Wiklund)



# Study Aims

- **Collect prospective families (N=~15,000 cases) with at least two gliomas - about 2% will have significant family history for linkage (N=~400 high-risk families)**
- **Identify regions of the genome where a gene candidate linked to familial brain tumors resides (Illumina)**
- **Further interrogate these gene candidate regions established in linkage aim by genotyping closely spaced genetic markers**



# Gliogene Infrastructure

- Developed web-based communication software (Plone) - password-protected website enables investigators to post documents (informed consents, protocols, papers, and training manuals) discussion forums
- Launched public website ([www.gliogene.org](http://www.gliogene.org))
- Working groups established and the screening and extended risk factor questionnaires finalized
- Training manuals for study staff and standardized sample collection protocols available on the website
- Developed secure web-based database to enter and transmit data, and draw pedigrees



# Gliogene Consortium Website

small text normal text large text



**GLIOGENE**  
International Glioma Research

home

you are not logged in

you are here: home

navigation

log in

Name

Password

## Welcome to the GLIOGENE Consortium Site

**Our mission is to create an international multi-center multidisciplinary consortium, to use the most sophisticated genetic analyses known to identify susceptibility genes in high-risk familial brain tumor pedigrees. This research team is uniquely positioned to characterize genetic risk of familial brain tumors and to conduct important translational research studies to enhance our understanding of brain tumor etiology.**

**Criteria:**  
We define familial brain tumors as those pedigrees in which two or more relatives have been diagnosed with a glioma unassociated with known genetic syndromes.

**Hypothesis:**  
There are specific discoverable genotypes that increase the risk of developing brain tumors.

**Aims:**

1. Establish a cohort of 400 high-risk pedigrees for genetic linkage analysis.
2. Identify candidate regions linked to familial brain tumors.
3. Fine map regions established in Aim 2 by genotyping selected SNPs from genome databases.

Created by [dzeng2](#)  
Last modified 11-06-2006 16:02 CST

upcoming events

April Conference  
Central Standard Time,  
05-01-2007

May Conference Call  
Central Standard Time,  
05-22-2007

<< **April 2007** >>

Su	Mo	Tu	We	Th	Fr	Sa
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30					



# Gliogene Public Website

## GLIOGENE



*International Glioma Research*

### GLIOGENE: An International Brain Tumor Family Study

#### **Brain tumors: Do they run in your family?**

Brain tumors are rare, and we don't yet fully understand what causes them. Very few appear to be hereditary, yet most brain tumors are associated with changes in an individual's genes.

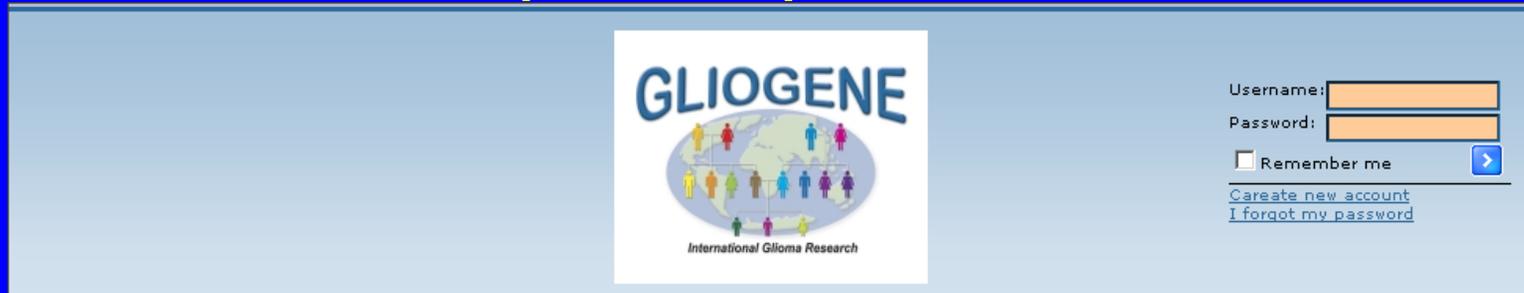
Part of the Public Web Page

<http://www.gliogene.org>



# Gliogene Data Website Site

This is only for the research team to entire data and is password protected



Username:

Password:

Remember me 

[Create new account](#)  
[I forgot my password](#)

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You must be a registered user to access this page. If you already have an account, please login with your credentials in the box on the upper-right corner. Otherwise [click here](#) to apply for an account.

Once logged in, this is the screen you will see:



Screen ▶

Interview ▶

Reporting ▶

Administration ▶

Support ▶

**GLIOGENE**  
International Glioma Research

Home

Hello .

▶ [Edit Profile](#) ◀

▶ [Logout](#) ◀

Welcome to the Gliogene Data Management System



# Long Screening Questionnaire

Screen ▶  
Interview ▶  
Reporting ▶  
Administration ▶  
Support ▶



Home > Screen > Long Form

Hello  
▶ [Edit Profile](#) ◀  
▶ [Logout](#) ◀

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## Long Screen Page 1 - Start

Search Type: Study ID/Family ID

Found GA0018 (with no SS and an LS) no LI

Go to page: 1 - Start

For Office Use Only:

Study Site	<input type="text" value="MDACC"/>	Study Identification	<input type="text"/>	Interviewer	<input type="text"/>
Today's Date	<input type="text"/>	Hospital	<input type="text" value="MDACC"/>	Personal ID/Medical Record#	<input type="text"/>

Choose a type for the patient:  Adult  Pediatric

Choose a type for the interviewee:  Proband  Proxy



# Summary Page of the Long Screening Questionnaire

- Screen ▶
- Interview ▶
- Reporting ▶
- Administration ▶
- Support ▶



Hello

[Edit Profile](#) ◀

[Logout](#) ◀

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**Long Screen Page 9 - Summary**

Search Type: Study ID/Family ID

Go to page: 1 - Start

**For Office Use Only:**

The quality of the data is: No input      Eligible for Linkage: No input      Participating: Yes

**Evaluation Criteria**

Count of family members with a glioma:

Count of family members with a cancer:

Does family have NF1:

DNA (Blood or tissue) is available on Proband:

Proband Glioma verified:

Type: No input

Consent Needed: No

IA Needed: Yes

PT Needed: No

**Assignment And Appointments:**

Assign To:  Assigned Date:

Contacted Patient: Yes Appt Day:

Blood Requested: No Blood Appt Day:

**Tracking:**

Type:

Tracking		CORE Registration				Pathology Abstraction					
Type	Date	Lab	Sample#	CORE#	COREID	DateOn	DateOff	Name	Code	DT Diag	DT Abs
Consent								Glioblastoma multiforme			

Type

- No input
- No input
- Consent
- Blood Collection
- Blood Delivery
- Saliva Collection
- Saliva Delivery
- Tissue Collection
- Tissue Delivery
- CORE Registration
- Medical Abstraction
- Questionnaire



# Gliogene Brochure English Version Cover

The Gliogene study is a collaboration among these participating institutions:

## IN THE UNITED STATES:

The University of Texas  
M. D. Anderson Cancer Center  
Baylor College of Medicine  
Brigham and Women's Hospital  
Case Western Reserve University  
Columbia University  
Duke University  
Evanston Northwestern Healthcare  
Memorial Sloan-Kettering  
Cancer Center  
Mayo Clinic Rochester  
University of California, San Francisco  
University of Illinois at Chicago

## IN EUROPE AND ISRAEL:

Gertner Institute, Israel  
Institute of Cancer Epidemiology,  
Denmark  
Institute of Cancer Research,  
United Kingdom  
Umea University Hospital, Sweden



## GLIOGENE An International BRAIN TUMOR Family Study

### QUESTIONS ABOUT THE STUDY

Please visit our website  
[www.gliogene.org](http://www.gliogene.org) or  
call 1-800-248-4856  
for more information and  
to register for the study.



THE UNIVERSITY OF TEXAS  
MD ANDERSON  
CANCER CENTER  
[www.mdanderson.org](http://www.mdanderson.org)

American Brain Tumor Association  
<http://hope.abta.org>

NBT  
NATIONAL  
BRAIN TUMOR  
FOUNDATION  
[www.braintumor.org](http://www.braintumor.org)

TUG MCGRAW  
FOUNDATION  
[www.tugmcgraw.org](http://www.tugmcgraw.org)



*"The Gliogene Project could lead to a genetic link to provide better treatments, prevention strategies and ultimately a cure for brain tumor patients and their families."*

Tim McGraw,  
Country Superstar and  
Honorary Chairman of the  
Tug McGraw Foundation.

The Gliogene study is funded by the United States  
National Cancer Institute 1R01CA119215-01A1  
and the American Brain Tumor Association.



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# Gliogene Brochure English Version Inside

## WHO IS ELIGIBLE?

To be eligible for participation in the Gliogene Study, families must have two or more biologically related members who have been diagnosed with a primary brain tumor known as a glioma. There are many different types of gliomas; some examples are astrocytoma, oligodendroglioma and glioblastoma multiforme.

Please visit our website [www.gliogene.org](http://www.gliogene.org) or call 1-800-248-4856 for more information and to register for the study.

## STUDY PARTICIPATION

If you decide to participate in this study, researchers will ask you to take part in a 45-minute research interview and risk questionnaire over the phone or in person. Researchers will ask participants and some of their family members to provide small blood samples to help identify possible genes related to the development of brain tumors.

Participants do not need to live near one of the collaborating institutions as all aspects of the Gliogene study can be completed via phone or mail.

## BRAIN TUMORS: DO THEY RUN IN YOUR FAMILY?

Brain tumors are rare, and we don't yet fully understand what causes them. Very few appear to be hereditary, yet most brain tumors are associated with changes in an individual's genes.

If you're concerned about your own or your family's risk of brain tumors and meet the study requirements, you may be eligible to participate in an International Brain Tumor Family Study called Gliogene.

## YOUR GENES AND CANCER

We inherit genes from our parents, and, over time, changes in our genes may occur. These changes are called genetic alterations and they may result in cancer.

Certain genetic alterations may place individuals at increased risk of developing cancer. This is why some cancers appear to run in families. If you have a particular genetic alteration, you may be at increased risk for certain types of cancer.

By providing a family health history and a small blood sample, brain tumor patients and their families significantly improve our ability to understand the hereditary factors of the disease.

## RESEARCH CAN HELP FIND THE ANSWERS

Gliogene is an international consortium of genetic brain tumor researchers in the United States, the United Kingdom, Sweden, Denmark and Israel.

Gliogene is the largest study ever to be conducted on malignant primary brain tumors, known as gliomas. Researchers aim to screen approximately 15,000 individuals worldwide during the five-year study.

With Gliogene, we may be able to learn more about possible genes related to this disease—and then identify a genetic link among family members of brain tumor patients.

Identifying a genetic link may provide information about the disease — information that one day we hope will lead to improved treatment, as well as prevention strategies.

## YOUR CONFIDENTIALITY IS ASSURED

All information that you provide, as well as your blood sample results, will be kept completely confidential. No one outside this study may have access to your information without your permission.

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# Gliogene Brochure Danish Version



Cover



A page from the inside



# Strengths of Gliogene

- Collaborative and committed group of investigators
- Members have access to data and can use the resource for supplemental funding
- Opportunities for junior investigators
- Developing criteria for publications that include junior and senior investigators



# Successes of Gliogene

- First manuscript in press
- IRB approval and data collection is underway at most institutions
- Case-Western and Columbia joined the consortium
- Chinese group would like to join and team is going to visit
- Second meeting is planned for November 2006



**This is Team  
Science.....**

