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ABSTRACT

The "Mapping the Human Genome" project demonstrated that librarians can help whomever they serve in accessing information resources in the areas of biological and health information, whether it is the scientists who are developing the information or a member of the public who is using the information. Public libraries can guide library users through the vast array of information and also provide opportunities for discussion and debate. This paper presents ideas for public library programs in the areas of biological and health sciences, as well as discussing opportunities for partnering among all different types of libraries so that libraries can provide this information to the public. Discussion focuses on the North Suburban Library System (NSLS), a consortium of over 650 academic, public, school, and special libraries in the suburbs north of Chicago, Illinois, which received a grant from the Department of Energy to develop information and programming about the human genome project through public libraries. The grant included focus groups, acquisition of library materials, publishing of periodic newsletters, development of a Web site and programs for the public. (AEF)

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Democratizing Human Genome Project information: a model program for education, information and debate in public libraries

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In the United States we often use the expressesion, " there is good news and there is bad news." This is an apt expression for my topic today.

The good news is that the amount of information and access to that information available on any subject is growing exponentially. People can find out what is happening as it happens. This is particularly true in the areas of biological and health information. What is the latest research? How do I make a decision about medical services? How will the new medical developments affect me?

The bad news is the amount of information is overwhelming. Information resources are difficult to find and confusing to use. We get data, not knowledge to make decisions about our lives. But then there is more good news. We know that in our expanding roles as librarians we assist individuals in finding and teach them to use information. We all gain, the scientist
when an informed citizenry understand the issues

Mapping the Human Genome project demonstrated that as librarians we can help whomever we serve – whether it is the scientists who are developing the information or a member of the public who is using the information. Public libraries can guide library users through the vast array of information and also provide opportunities for discussion and debate.

The biggest headlines about genetics were grabbed by Dolly the cloned sheep, but there's much more to the story than a wooly lamb. The real story is the discovery of the sequence called the human genome—the genetic map that tells us not only who we are, but also where we came from, and maybe even where we're headed.

Next year will bring two more major news events that are likely to put the genome and its implications back on the front pages. The final draft of the genetic sequence will be announced. 2003 marks the 50th anniversary of the discovery of DNA by James Watson and Francis Crick. Libraries of all types must start planning now for resources and programs that will help put our libraries on the genetic map.

The topic is ideally suited to public libraries as public forums. The issues are the kinds that libraries have always been best at exploring and explaining. They pull together science and philosophy, history and fiction, and require sifting and sorting information.

As journalist Steve Olson says in *Mapping Human History: Discovering the Past Through Our Genes*:

> "The story written in our DNA is one of great promise, not peril. Besides, it's one of the best stories you'll ever hear. It has adventure, conflict, triumph, and sex—lots of sex. It ranges from jungles to deserts to icy plains, across generations and thousands of years. It's the story of us, from our humble origins on the savannas of Africa to a position of unprecedented mastery over our own future."

My purpose here today is not only to present ideas for public library programs. But also, I would like to stimulate ideas for partnering among all different types of libraries to provide this important information to the public. Public libraries are ideal partners for any biological or health sciences library. In the United States, public libraries:

- Offer free access to ideas and information
- Serve the entire community as a center for reliable information
- Provide opportunity and encouragement for children, young adults, and adults to continually educate themselves
- Provide an open and non-judgmental environment in which people and their interests are brought together with the universe of ideas and information.
- Offer the practical information people need to improve their quality of life and to increase individual options in a complex society.
- Deliver information and education in a variety of formats via materials and programming.

The North Suburban Library System (NSLS) is a consortium of over 650 academic, public, school, and special libraries in the suburbs north of Chicago, Illinois in the United States. It is one of 12 Illinois library systems funded by yearly grants from the State of Illinois. The most important responsibilities of library systems are to promote library development and facilitate resource sharing among libraries.

Agencies of the United States government have supported the mapping of the human genome for over ten years. The U.S. Department of Energy (DOE) and the National Institutes of Health (NIH) have devoted 3% to 5% of their annual Human Genome Project (HGP) budgets toward studying the ethical, legal, and social issues (ELSI) surrounding availability of genetic information.

The North Suburban Library System received a grant from the Department of Energy to develop information and programming about the human genome project through public libraries. The grant included focus groups, acquisition of library materials, publishing of periodic newsletters, development of a Web site and programs for the public.

After the grant award was announced, the major local newspaper printed an editorial, entitled Sharing *the Knowledge.* It stated:

> Library...personnel should be praised for pursuing the grant and for their vision in recognizing a library's need to become a player in this ...period of explosive genetic research.
>
> These exciting times will generate incredible scientific advances, as well as passionate discourse. It is good to know that our local libraries, repositories of the human condition, are playing a role.

Far from being too complicated or too esoteric and exotic, the libraries in the pilot project discovered that the topic has something for everyone. From secondary students in Elk Grove Village getting a visit from one of the people who works on the X-Files, a popular television program about alien life forms, to a family DNA Day in Highland Park, the project generated an enormous variety of program formats, topics, and audiences. Programs ranged from book discussions and film series to panels with medical experts, scientists, lawyers, ethicists, police detectives, linguists, philosophers—it's a topic that seems to generate debate and opinion, as much as facts and information. Presenters ranged from academics and scholars to sci-fi creators and puppets.

As Martha Nussbaum and Cass Sunstein, editors of *Clones and Cloning*, write in their introduction:

> "These questions can be posed by science, and science can give us real facts....Science, however, doesn't give us the answers to the ethical, political, social, and religious questions raised by cloning. These answers need to be worked out, ultimately, in the course of public debate. But the humanities and the social sciences can help us lay out the options in a clear way, and give us good arguments to ponder."

Participating librarians felt the need for background information . To talk about genetics, you have to talk about more than just science. It's part fact, part fantasy, a blend of cutting-edge discoveries and age-old questions. Questions like what makes a human life unique, how do we reconcile knowledge with belief, can we live longer, better, or even forever?

What exactly is the human genome and what does it mean for ordinary people? The genome—basically, the genetic material that makes a sheep a sheep and a human a human, so to speak—is a hot topic. Dolly was just the first of the headlines. Since then, there's been a steady stream of new discoveries, controversies, and revelations.

Since the announcement in June 2000 that the mapping of the genome was essentially complete, and something that had previously been mostly in the hands of scientists and laboratories was suddenly available for public consumption. Daily newspapers carried pages and pages of coverage and the news was widely compared to the landing of man on the moon. At the time, major issues of popular magazines pledged to devote entire upcoming issues to the topic. [*Nature*, Feb 15, 2001 and *Science*, Feb. 16, 2001, both accessible online: www.nature.com, www.sciencemag.com]

Several sites offer good background information for a range of audiences, from professionals on down to children. Some of these will take some searching to get just the information you want, but they're all worth a look. Look at the NSLS Genome Took Kit for the most up to date sites.

For an overview of the NSLS project, visit www.nsls.info/genome. The site offers background on the project, as well as four issues of an informative newsletter with articles, program listings at participating libraries, and annotated bibliographic information on books and films for collections and discussion series.

The participating libraries had to find the focus in each of their communities. This a vast subject, with almost as many subtopics as the number of genes in a typical genome (30,000 to 40,000, in case you were wondering.) One of your first tasks will be to narrow the topic down to areas that interest your patrons. The libraries in the NSLS pilot project used focus groups made up of selected patrons and partners to explore the topic.

As one of the participating librarians summed it up, "Find out what they want to know. Then get them what they need."

Twelve focus groups were held in the participating libraries. A group of library patrons were asked about their knowledge, feelings, hopes and fears about the human genome project.

Key issues that came up in every group:

- Moral and ethical implications of the Human Genome Project,
- Privacy of genetic information and the possible loss of insurance or employment,
- Using genetic information to "design" future generations,
- Ownership of the information and therapies derived from the project.

Some of the many questions asked by focus groups participants included:

- Could genetic information be a source of blackmail if someone gets your record?
- What is a pre-existing condition and what's not?
- Who owns the genome?
- Who is going to control and finance it?
- Can you replace genes? Where are we on this process?
- What will it do to evolution?
- Will it increase competition and stress if we're all alike?
- Who decides what kid is perfect?
- Is this against God's will?
- What is the underlying science in the Human Genome Project?
- Who will have access to the information?
- What if testing became mandatory or done without consent?
- Will neighbors be talking about your genetic code?

Types and kinds of topics relating to the HGP mentioned by the focus groups included:

- Knowing more about the science underpinning the genome project
- Privacy of genetic information, including implications for insurance or employment if someone knows your genetic predisposition
- Using genetic information to "design" future generations
- Who "owns" the genetic code and issues of private vs. government research
- Prospects for medical advancement

People will typically focus on the specific causes and concerns that apply to them. The job of the librarian is not only to listen, but also to translate these interests into programs that will have broad appeal. Most of the same techniques and principles that apply to library programming in general will still apply here.

While each participating library in the pilot project presented programs that were unique to their communities, some general trends and tips can be distilled from their collective experience:

- Involving a group of libraries—a system, a cooperative or service area, even a statewide project—can lead to sharing of resources and strengthen the overall effort.
- The fact that the Human Genome Project is in the news and likely to be back on the front pages in 2003 can help with publicity and coverage in the local media. Make sure your local newspaper knows your schedule of events so they can tie-in to hard news stories as they develop
- This is a serious issue, and it will take effort to build audiences. Partners such as senior centers or religious groups that provide "captive" audiences can be a real asset, as can media partners that help get out the word.
- A series of programs is a good approach to both build audience interest over time and allows you to tap into the many different facets of the topic.
- Getting off to a good, strong start will help immensely in sustaining momentum among library staff, audience and potential audience members, and the community at large.
- A creative approach to finding speakers can pay big dividends. Two of the most interesting programs resulted from recommendations from local science teachers that led to prominent and fascinating national speakers.
- Decide whether you're aiming for breadth or depth with certain programs. For example, programs that target specific genetic conditions—such as testing for predispositions to cancer or hereditary tendencies in racial groups—are much more likely to draw small audiences with a strong interest in the topic than general audiences. On the other hand, broad topics like DNA can be developed into programs for the whole family.
- Less might be more. Too many programs on too many topics with too many speakers can lead to too few people in the audience. You don't need to cover all the bases with this first series—explore a segment of the topic with a targeted audience, and if there's interest, add more programs to your next calendar of events.
- The topic is a natural for mixing seniors and young adults, often to good effect. The young adults are much more comfortable with the science, and the seniors often have a strong health interest. Libraries that drew these two groups to the same programs were surprised and pleased with how well the two combined.

- Support from the library administration is key. Not only will they understand the amount of time this type of programming takes, but also they can help facilitate partnerships with other organizations at the decision-making level.

Resources

Once you've got the basics in place, the single most important ingredient in programming of this type is developing a resource base to draw on for speakers, topics, information, and audiences. Local partners are a key ingredient in this mix, but there are lots of other things to stir in.

Local Partners

All of the libraries in the NSLS pilot project developed strong local partners. Examples of partners and their roles include:

- High schools and youth groups provided not only access to teens, but also the expertise of high school science teachers. Libraries reported generally increased library usage by students not only during the project, but subsequently.
- Senior centers are logical partners for many library programs, as they offer a built-in audience with flexible schedules and free time. In the case of genetic programming, they would seem most likely to be interested in programs that focus on medical benefits, but don't underestimate the breadth of their interest. They can prove to be excellent audiences for film series and book discussions on the larger ethical and social questions involved.

- Hospitals and health care agencies can provide information and speakers, and promote programs to their clientele.
- Universities are excellent sources for speakers who can explore the dimensions of the topic beyond the purely medical or scientific. Philosophical, legal, and historical approaches, as well as literary and artistic aspects, can lead to a much more varied programming approach.
- Membership groups, such as Rotary Clubs or Chambers of Commerce, are valuable assets in engaging the broader community.
- Religious or faith-based groups may have specific interests in the topic, but also offer access to community members and meeting space.

National Sources
The major issues that relate to the topic—science, health, law, history, philosophy—all have national and international organizations that can be helpful in providing information, and possibly speakers. Here's a partial listing to help you get started, but one of your best routes to these organizations may be through local contacts that happen to be members or attend national conferences, etc.

- Professional Organizations

(e.g., American Medical Association, American Bar Association)
For example, the American Medical Association home page (www.ama-assn.org/) is a good place to start. A search with simply the term "genome" turns up a concise, 5-page article in reprintable form titled "Implications of the Human Genome Project for Medical Science" (http://jama.ama-assn.org/issues/v285n5/ffull/jsc00413.html). The article is coauthored by

Francis Collins, who led the HGP research, and while it dates from February 2001 and appeared in a medical journal, it is an excellent readable and current outline of the issues.

- Health and Science Education Organizations

The National Science Teachers Association holds an annual conference and lists speakers and their bios on their website. (http://www.nsta.org/conventionsupport&record_id=27&Meeting_Code=2002SND)

Other organizations for the teaching of science that can be helpful with both topic and speaker ideas include the National Center for Science Education (www.natcensied.org) and the National Association of Biology Teachers (www.nabt.org).

The NSLS website has descriptions and links to sites that focus on genetic conditions and additional educational resources. www.nslsilus.org/genome/resources.html

- Media

National magazines like *Science* and *Nature* have fully searchable websites and have devoted extensive coverage to the topic of the human genome. See especially:
Nature, Feb 15, 2001, www.nature.com/genomics/, and
Science, Feb. 16, 2001, www.sciencemag.org/content/vol291/issue5507/
The *Nature* site in particular has a wealth of information and links to additional sources.

The New York Times website (www.nytimes.com/library/national/science/genome-index.html) has a separate section on the project that includes an index of articles, as well as a video, interactive images, an online discussion forum, and extensive links.

The NPR radio feature, *Science Friday* with host Ira Flatow, has several archived audio files of programs they've aired on the topic. www.sciencefriday.com/pages/genes.html

The Discovery Channel presented *The Real Eve*, a documentary produced by Paul Ashton on the increasingly accepted DNA-based research that all humans alive today are descended from a common female ancestor living in Africa about 150,000 years ago.
http://dsc.discovery.com/convergence/realeve/realeve.html

- Government

The two main federal United State sites are the agencies that partnered in the publicly funded effort to sequence the human genome. Both sites have extensive information and links for public education, as well as more technical information for scientists.

Department of Energy Human Genome Project Site
www.ornl.gov/TechResources/Human_Genome/home.html

National Human Genome Research Institute
www.nhgri/nih.gov

- University-based Projects

Many U.S. and foreign universities have genome-related projects with public education components that reach beyond their local communities. For example:

"The Human Genome Project: Progress, Problems, and Prospects," a panel presented by Northwestern University in April 2002 is available via an archived web cast (www.northwestern.edu/science-outreach.genome). A discussion by a panel of experts "in plain English, for non-scientists" on the medical, ethical, and legal implications of the project, the webs cast offers a chance to hear and see what this type of program is like.

The High School Human Genome Program at the University of Washington (www.hshgp.genome.washington.edu) provides professional development in the field of DNA sequencing and genomics for high school teachers, primarily in the Seattle area. But through their website and a summer institute, they also offer virtual resources for developing DNA sequencing units for classrooms in their communities.

This website—www.biology.arizona.edu/--is recommended by high school science teachers who worked with the NSLS Human Genome Project libraries as one with good interactives on DNA and other human genetics topics.

Speaker Referrals

Finding the best speakers is a combination of resources, research, luck, and geography. The NSLS libraries often found the best speakers through recommendations from their partners. For example, high school and college-level science teachers can sometimes suggest a dynamic speaker they heard at a professional meeting or conference, or a local doctor or professor may know of a colleague who is an expert in the field.

Local speakers are often the best choice, not only because of cost, but also because their connections and commitment to the community may enhance their effectiveness. But don't limit yourself exclusively to local presenters. If you present a series of programs, you may find that a nationally known speaker or author is a great way to draw attention and end up with bigger audiences for all your programs.

Collections

Popular and "Real" Science

Powers, Richard. *The Gold Bug Variations*. Harper Perennial, 1992. Voted the #1 novel of the year by *Time* magazine in 1991, it predates the factual decoding of the genome but explores a librarian's obsession with the secrets of genetic coding in a story with love and music, as well as science and sleuthing.

Simon, Anne. *The Real Science Behind the X-Files: Microbes, Metorites, and Mutants.* Simon & Schuster, 1999. Simon, a university professor who worked as an advisor to the television series, offers an episode-by-episode glimpse into the science behind the scenes.

Carina, Dennis & Gallagher, Richard. *The Human Genome*. Palgrave: St. Martin's, 2002. A concise overview to help the lay reader understand the human genome—the basics of DNA, genetics, and the Human Genome Project—edited by two of the editors of *Nature* magazine.

Bios and Background to the News

Davies, Kevin. *Cracking the Genome: Inside the Race to Unlock Human DNA*. Free Press, 2001. Documents the public-private competition between Francis Collins and J. Craig Ventner, bringing both the scientists, and the science, to life.

Weissmann, Gerald. *The Year of the Genome: A Diary of the Biological Revolution.* Times Books: Henry Holt and Company, 2002. In a series of reflections on events relating to the human genome from mid-2000 through 2001, the book offers a literate and wide-ranging reflection on the breaking news stories.

History and Commentary

Nussbaum, Martha C., and Sunstein, Cass R. *Clones and Cloning: Facts and Fantasies about Human Cloning.* W. W. Norton, 1999. The collection includes essays by Stephen Jay Gould, Andrea Dworkin, and other provocative pieces in sections entitled Science, Commentary, Ethics and Religion, Law and Public Policy, and Fiction and Fantasy.

Olson, Steve. *Mapping Human History: Discovering the Past Through Our Genes*. Houghton Mifflin Company, 2002. Tracing the beginnings of mankind as explained by the mapping of the human genome, this sweeping panorama of the globe offers a basis for discussing both our commonality and variety as humans.

Sample Programs

While the libraries in the pilot project planned and presented their own programs, NSLS cosponsored a kickoff event for all the libraries in the system. "What Does the Human Genome Project Mean for You and Your Family" was a panel discussion moderated by Chicago Public Radio host Mara Tapp and featuring a mix of legal, medical, and scientific voices on the ethical, social, and legal implications on the project. The program was held on a weekday evening at the North Shore Center for the Performing Arts in Skokie and drew an audience of 350 people.

Other system-wide resources included speaker referrals, a website, and regularly published newsletters, all available at the project website, www.nsls.info/genome.

Family Programs

Highland Park Public Library hosted a Sunday afternoon "DNA DAY" for families with children ages 5 and up featuring science stations to explore the mysteries of DNA, genes, the Human Genome Project,

genetics, and more with hands-on fun and experiments. It was so successful, the library decided to make it an ongoing event at least every other year. "We'd do it every year, except it takes a TON of staff time," according to librarian Gail Juris.

Two of the participating libraries partnered with Health World Children's Museum, which created Human Genome Discovery Boxes for use at the museum and both libraries. The boxes include charts, posters, models, books, interactive activities, games and written materials with

activities and resources for individual to take home. For more information, visit the museum website, www.healthworldmuseum.org.

Book Discussions

Winnetka-Northfield Public Library held a book discussion series with the following titles:

Ridley, Matt. *Genome: the Autobiography of a Species in 23 Chapters.*
Pollen, Daniel A. *Hannah's Heirs: the Quest for the Genetic Origins of Alzheimer's Disease.*
Beck, Martha Nibley. *Expecting Adam: a True Story of Birth, Rebirth and Everyday Magic.*
Drabble, Margaret. *The Peppered Moth* (fiction)
Reilly, Philip R. *Abraham Lincoln's DNA and Other Adventures in Genetics.*
Henig, Robin Marantz. *The Monk in the Garden: the Lost and Found Genius of Gregor Mendel, the Father of Genetics.*
Wexler, Alice. *Mapping Fate: A Memoir of Family, Risk and Genetic Research.*
Sykes, Bryan. *The Seven Daughters of Eve: The Science That Reveals Our Genetic Ancestry.*
Andrews, Lori B. *Future Perfect: Confronting Decisions About Genetics.*

Several other libraries held book discussions as well, with Matt Ridley's *Genome* being among the most popular titles.

Panels

Panels were often used to present various sides of the issue, ranging from legal, social, medical, ethical and humanistic concerns. Panelists were typically drawn from local universities, hospitals, museums, law firms, etc. A moderator, such as the science editor of a local paper or radio personality, can help keep the discussion moving and also draw an audience.

Skokie Public Library presented a two-person panel, "Genes and Genealogy: Where Have You Been?", exploring the parallel evolution of the human genome and the development of language associated with the migrations of mankind. The presentation combined anthropology, linguistics, psychology, ecology and evolution.

Lectures

Subjects of lectures and informal talks included:

A Century of Genetics: From Mendel to the Genome
Jewish Genetic Disorders
Are You at Risk for Cancer?
The Human Genome Project and Its Impact on Seniors
Carrier Screening: We Are All Mutants

One of the partners of the Gail Borden Public Library District in Elgin was the community college, and a biology professor at the college recommended a speaker he had heard at a conference, Dr. Sam Rhine. Rhine, who directs the Genetic Education Center in Indianapolis presented a lecture, "The Human Genome Project: A Glimpse Into 21st Century Technology," that turned out to be the library's most well attended adult program of the year.

Several libraries offered a program titled "Solving Crimes with DNA," presented by Ron Fridell, author of *Solving Crimes: Pioneers of Forensic Science.*

Youth Programs
The Elk Grove Village Public Library partnered with Elk Grove High School to present two programs with Dr. Anne Simon, science advisor to the television series, *The X-Files.* Librarian Lisa Malinowski and science teacher Deb Conners were brainstorming ideas when Conners mentioned a book written by Simon that one of her students had read and raved about. Malinowski contacted the author, who agreed to present programs both at the high school and at the library on "The Real Science Behind The X-Files." The students also participated in a creative writing contest, submitting fiction and poetry.

In general, Conners suggests that programs that emphasize nontraditional subjects and "real" experiences will appeal to high school students. "I teach a crime science class that's very popular," Conners says, "but not every high school has classes like this. If libraries bring in things like local law enforcement agencies that work with science and crime, I think kids would come." Another idea from Conners is to develop a summer school class on the chapters from the *X-Files* book.

Film Series
Northbrook Public Library presented a film and discussion series, "Genetics in Cinema" with films including:

Gattaca
Island of Lost Souls
Twilight of the Gods
Jurassic Park

Tools: Planning Checklist
As you start to plan a library series on this or any topic, you'll find that programs with clear goals are the easiest ones to produce. At the same time, programs with goals that serve various aspects of the library's mission—for example, ones that cross several departments, capitalize on assets in your community, and are timed to coincide with other themes or projects—will be popular and easier to promote. Finding strong connections between related goals will build the most successful programs.

Audience goals
- Identify your target audience: demographics, interests, new users?
- How many: space limits, how to maximize?
- Why this audience: prior indication of interest?
- What do you know about their current level of knowledge?

Topic/collection goals
- Are you focusing on pure science?
- Medical/health issues?
- Legal and ethical concerns?
- Historical context, such as common racial origins?
- Is there an area of the collection that you want to emphasize or build?
- Themes that relate to other library or community programming?

Community goals
- What issues/agendas are primary in your community?
- What partner organizations share some of your goals?

Program goals
Specifically, what do you want the program to accomplish:
Inform people?
Draw attention to the library as a resource?
Provide a forum for discussion in the community?
How will the library benefit?
How will you be able to continue/maintain the programs?

Tools: Partnership Checklist

Libraries in the pilot project reported varying degrees of satisfaction with individual partnerships, but all agreed that the best partnerships produced the best programs.

Make a list of organizations that
- share the same goals as the project
- bring something to the project that you don't have
- want to reach your project audience
- might benefit from the project

Get ideas from other library staff for possible partner organizations—consider businesses, as well as nonprofit groups and individuals.

The following outline can help both you and the partner understand the relationship:
- *Briefly* brainstorm the answers to these two questions to focus your thinking about the roles of the library and partner:
  - What strengths does the library bring to the project?
  - What strengths does the partner bring to the project?

- Discuss and list possible responsibilities/tasks for the library and partner:
  - What are the primary responsibilities of the library in the project?
  - What are the primary responsibilities of the partner in the project?

- Consider how activities will be divided:
  - Which responsibilities are shared?
  - How will these be coordinated?

- Create a "job description" for each agency (the library and each partner) that can serve as a sort of "operating agreement" between the organizations.

The Future?

The future for the genome project and its impact on all of us on the planet is breathtaking. As libraries we can partner with each other and provide the information that all people need to understand the basic concepts, find resources and make decisions.

The toolkit we put together is just a beginning. I hope that this site can become an international site with examples of resources, ideas and library services provided by library institutions all over the world. Please send your information to me and we can create a more useful site for all of us.

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