Be a part of the vision of the State Genetics Plan. Help shape the future of improved health outcomes and enhanced quality of life for Michigan citizens through appropriate use of genetic information, technology and services.

Register by Friday, April 15, 2005, to ensure your seat at the Summit!
Dear Genomics Partners and Stakeholders:

The Michigan Department of Community Health cordially invites you to attend the 2005 Michigan Summit on Genomics and Public Health. The Summit will be held on Monday, May 2, 2005 at the Lansing Center in downtown Lansing.

During 2001 and 2002, we enlisted the help of nearly 1,000 Michigan citizens to participate in a statewide needs assessment. The collaborative work of those stakeholders and experts led to development of our state plan, Genetics Through the Life Cycle: Improving Health and Preventing Disease. Since 2003, considerable progress has occurred, with many of the suggestions gathered during the needs assessment process being implemented to address specific objectives. However, there is still work to be done before the plan’s six goals are fully achieved. You are a key partner in this groundbreaking work and we value your participation in the Summit!

The purpose of the 2005 Summit is to:

- Reconnect with state and local partners who participated in the development of the State Genetics Plan, to provide a mid-course review with updates on accomplishments to date;
- Provide an opportunity for our federal partners to share their vision of the future for nationwide public health activities addressing birth defects, newborn screening and genetic service delivery, and genomics;
- Solicit input from new partners and stakeholders on future activities and action steps that are still needed to achieve the goals of the State Genetics Plan.

The Summit will provide an opportunity for you to: (1) receive updates on state and federal programs and projects; (2) network with key stakeholders; and (3) participate in one of 11 facilitated work groups to identify “next steps” for particular issues related to the core goals of the plan.

Please take a moment to study the enclosed agenda, particularly the work group descriptions. Then, use the registration form to reserve your seat at the May 2nd Summit. We encourage you to submit an abstract for a poster presentation, as well as nominate an individual or organization for the Director’s Recognition Award which will be presented at the Summit. Information on these opportunities can also be found in the brochure. Thank you for your interest and we hope to see you at the Summit!!

Sincerely,

Janet Olszewski
Director
Who should attend?
The Summit is intended for anyone who is interested in the goals and activities of the State Genetics Plan and working in related fields, including:

- Clinical providers, both primary and specialty care
- Community-based service providers
- Consumers, family support and advocacy groups
- Educators
- Faith-based representatives and clergy
- Health plan representatives
- Laboratory providers
- Media
- Policy makers
- Private industry and foundation representatives
- Public and mental health representatives
- Researchers

Location and Guest Rooms
The Summit will be held at the Lansing Center, located downtown at 333 East Michigan Avenue, Lansing, Michigan 48933. A small block of guest rooms has been held at the Lansing Radisson Hotel, adjacent to the Lansing Center at a rate of $149.95 plus tax. Directions and a map are found on page 8 of this brochure, or you may check www.lepfa.com. To make a reservation at the Radisson, please call 517-482-0188 by April 1. All hotel charges are the responsibility of each individual.

Cancellation Policy
Cancellations for the Summit, with a full refund, will be accepted through Monday, April 25. Cancellations must be received in writing, by e-mail or fax, to the management office. (DMSdiane@concentric.net or 517-663-5245). No refunds are available after April 25.

For more information on registration, award nominations and poster submissions:
Contact Diane Drago at DMSdiane@concentric.net or 517-663-5147.

For more information on the Summit agenda:
Call toll-free 1-866-852-1247 or e-mail genetics@michigan.gov

Genetics Through the Life Cycle: Improving Health and Preventing Disease
The State of Michigan Genetics Plan includes six core goals.

1. Increase genetic literacy in the State of Michigan.
2. Assess the public health impact of heritable conditions and the utilization of genetic services.
3. Improve access to genetic information, prevention strategies and services.
4. Promote early identification and treatment of individuals with birth defects, heritable disorders or genetic susceptibilities, throughout the life cycle.
5. Identify best practices and promote a policy framework to assure high quality services, supports, and genetic privacy protections.
6. Promote appropriate public health responses to advances in genomic medicine and technology.

See page 10 for information on submitting a poster presentation on your research or programmatic activities related to these core goals.
AGENDA

8:00 a.m.
Registration opens
Continental breakfast in Exhibit/Poster area

8:30 a.m.
Welcome and Opening Remarks
Jean C. Chabut, BSN, MPH
Chief Administrative Officer, Public Health Administration
Michigan Department of Community Health

Introduction of Partners
Stakeholder groups participating in the Summit will be recognized.

8:50 a.m.
Overview of the State Genetics Plan: Needs Assessment and Accomplishments
Janice Bach, MS, State Genetics Coordinator
Michigan Department of Community Health

9:10 a.m.
Michigan Demonstration:
Genetic Education and Needs Evaluation (GENE) Project
Othelia Washington Pryor, PhD, Assistant Professor
Department of Medicine, Office of Medical Education Research and Development, Michigan State University

Dr. Pryor will present a brief overview of the GENE Project, an example of a national community-based genetics education project.

9:30 a.m.
Stretch Break

9:45 a.m.
The Future of Genomics: The Federal Perspective
MODERATOR: Jean Chabut, BSN, MPH
Michigan Department of Community Health

Birth Defects and Developmental Disabilities
Coleen Boyle, PhD, Director, Division of Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention

Birth defects and developmental disabilities have a profound impact on public health. Dr. Boyle will discuss that impact, the current data on prevention strategies, and provide some “best practice” examples of prevention and follow-up systems. Included in this discussion will be an overview of CDC’s birth defects and developmental disability activities, where Michigan stands relative to other states, and examples of the collaborations necessary to reduce the occurrence of birth defects and assure linkage to services.

10:15 a.m.
Healthy People 2010 and Genetic and Newborn Screening Services
Michelle Lloyd-Puryear, MD, PhD
Chief, Genetic Services Branch
Health Resources and Services Administration (HRSA)
Maternal and Child Health Bureau

This wide-ranging presentation will include an overview of the Healthy People 2010 goals, the HRSA initiatives relating to genetics and newborn screening, integrated child health information systems, and the existing genetic health disparities and barriers to ensuring access to services and genomic medicine. Dr. Lloyd-Puryear will review where Michigan stands relative to national recommendations for newborn screening and share her vision of the future.
10:45 a.m.
Break in the Exhibit/Poster Area

11:15 a.m.
Work Group Sessions—Part I

NOTE: The work group sessions are one of the most critical aspects of the Summit. All participants are asked to pre-register for their TOP TWO working group session preferences. Your work group will be confirmed prior to the Summit and you are asked to attend the same session both at 11:15 a.m. and 2:00 p.m. Each group will be led by a trained facilitator and scribe, but these sessions have been designed to be interactive, working sessions.

Each work group will be presented with a status report on activities and progress to date in that area. Participants will then be asked to identify any new objectives and action items that should be added to the State Plan, and then prioritize objectives in that area.

Work Group A: Access to Genetic Services

Issues which may be discussed relative to the objectives and action items in access to genetic services include: (1) access to genetic evaluation and risk assessment services; (2) geographic distribution of clinics; (3) referral patterns; (4) third party coverage; (5) out-of-state testing; (6) the role of the primary care service delivery system; (7) the need for a genetically literate health workforce; and (8) the benefits and challenges of using telemedicine as a way to increase access to services.

Work Group B: Birth Defects Prevention

Issues which may be discussed relative to the objectives and action items in birth defects prevention include: (1) recent state and national birth defect prevention strategies including folic acid campaigns; (2) the first Michigan Birth Defects Registry annual report; (3) ways to use data for targeting and evaluating prevention efforts; and (4) increasing community-based partnerships to promote birth defects prevention.

Work Group C: Cancer Genetics

Issues which may be discussed relative to the objectives and action items in cancer genetics include: (1) existing statewide cancer genetics initiatives, including the Michigan Cancer Genetics Alliance; (2) unmet needs relating to educational outreach; (3) special populations; (4) the role of family history; (5) access to cancer risk assessment services; and (6) the establishment of a data system to monitor hereditary cancers.

Work Group D: Educating the General Public

Issues which may be discussed relative to the objectives and action items in education include: (1) increasing the genetic literacy of the general public by providing genetics education through schools and community-based groups; (2) identification of specific target populations; (3) ways to collaborate with Michigan teachers, the media, community groups and other potential partners; and (4) how to monitor progress in educating the public and increasing genetic literacy.

Work Group E: Emerging Technologies and Treatments

Issues which may be discussed relative to the objectives and action items in emerging technologies and treatments include: (1) new or emerging genetic technologies and treatments that have the potential to impact the public’s health; (2) pharmacogenomics; (3) DNA-based enzyme treatments; (4) nutrigenomics; (5) individualized medicine; and (6) the role of public health in relation to private industry, health care systems and other partners interested in these new advances.
11:15 a.m.
Work Group Sessions—Part I continued

**Work Group F: Genes and the Environment**

Issues which may be discussed relative to the objectives and action items in genes and the environment include: (1) steps for addressing the potential public health impact of interactions between the human genome and physical environment; (2) identification of existing studies and data sources within the state; (3) ways to assess current environmental exposures from a genomics perspective; (4) ways to increase collaboration between toxicogenomic research, occupational health, and public health; and (5) how to educate the public to better understand emerging applications of gene-environment science.

**Work Group G: Genetic Testing and Laboratory Issues**

Issues which may be discussed relative to the objectives and action items in genetic testing and laboratory issues include: (1) genetic testing and laboratory issues pertinent to public health; (2) the growing trend of direct-to-consumer marketing; (3) quality assurance; (4) informed consent for genetic testing; and (5) billing/reimbursement.

**Work Group H: Integrating Genomics in Chronic Disease Programs**

Issues which may be discussed relative to the objectives and action items in the integration of genomics in chronic disease programs include: (1) the progress to date of incorporating genomics into existing chronic disease prevention programs such as asthma, cardiovascular health and nutrition, diabetes, WISEWOMAN, osteoporosis, and others; (2) strategies to increase awareness of underlying genetic disorders that can lead to common chronic disease manifestations; (3) ways to incorporate genomics and the use of family history in population-based screening, data collection and prevention; and (4) identification of potential new partnerships with local public health and community-based programs.

**Work Group I: Linking Families to Services**

Issues which may be discussed relative to the objectives and action items in linking families to services include: (1) the role of public health and other service providers in linking children with special health care needs to services; (2) existing resources; (3) strategies to assure that families who receive a prenatal or pediatric diagnosis of a birth defect or genetic condition are connected with information about available resources and community-based services; (4) priorities for improving and standardizing the information; and (5) ways to support the concept of a medical home for children with special health care needs identified by newborn screening or other diagnostic methods.

**Work Group J: Expanded Newborn Screening**

Issues which may be discussed relative to the objectives and action items in newborn screening include: (1) an update on plans to expand Michigan’s screening panel; (2) how to implement expanded screening (3) confirmatory testing; (4) short term and long term follow-up needs; (5), educating the public; and (6) increasing family involvement in the newborn screening program.

**Work Group K: Transition Issues and Genetic Health Care for Adults**

Issues which may be discussed relative to the objectives and action items in transition issues and genetic health care for adults include: (1) improving the transition for children with birth defects and genetic conditions to adult health care systems; (2) identification of existing models within the state; (3) gaps in services for adults with developmental disabilities and genetic disorders; and (4) ways that families, health care providers, health plans, and other organizations can work together to make improvements.
12:15 p.m.
Director’s Recognition Award
Janet Olszewski, Director
Michigan Department of Community Health

12:30 p.m.
Lunch

1:15 p.m.
The Future of Genomics, Public Health and Disease Prevention
Muin Khoury, MD, PhD, Director
Office of Genomics and Disease Prevention, Centers for Disease Control and Prevention
Dr. Khoury will wrap up the federal perspective with a discussion of the potential benefits of genomics in public health, specifically related to chronic disease prevention and gene-environment interactions. He will provide examples of public health responses to advances in genomics technology, the evidence-based processes and collaborations necessary to integrate genomics into health care and prevention programs, and the barriers that we are still facing. Dr. Khoury will leave us with his vision of Michigan’s status and future in the genomics revolution.

2:00 p.m.
Work Group Sessions: Part II
Participants return to their work groups to complete their discussions and recommendations.

3:15 p.m.
Break and return to main ballroom

3:30 p.m.
Work Group Reports
The facilitator from each work group will present a three-minute highlight overview of the discussion and recommendations.

4:15 p.m.
One Family’s Story
Julie Greichunos
A grandmother will share the story of her family’s experience and why she decided to become involved as an advocate helping to improve and expand Michigan’s newborn screening and genetic services system.

4:30 p.m.
Closing remarks and adjourn

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The Michigan Department of Community Health appreciates the work of the Genomics Summit Advisory Committee in developing the program.

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<tr>
<th>Janice Bach, Committee Chair</th>
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<td>Michigan Department of Community Health</td>
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The Genetics Plan Revisited

333 East Michigan Avenue, Lansing, MI 48933

Additional driving and parking information will be mailed with your confirmation and parking pass.

**Parking**

The primary parking lot is beneath the Lansing Center. Enter lot from Museum Drive.

**Additional Parking Can Be Found At:**

A. North Grand Parking Ramp
   Enter from Northbound Grand Ave. Take the PEDWAY on the third floor to the Lansing Center or Radisson Hotel.

B. South Grand Parking Ramp
   (2 blocks from the Lansing Center) Enter from Northbound Grand Ave.

**Driving Directions To The Lansing Center**

**From the Detroit Area:** Take I-96 west to I-496 west/downtown exit. Continue on I-496 to the Cedar/Larch and Pennsylvania exits.

Follow the Cedar/Larch signs and exit right onto Larch going north. Larch to Shiawassee and turn left. Go one block to Cedar; turn left. Turn right onto Museum Drive and follow signs for parking under the Lansing Center.

**From the Grand Rapids Area:** I-96 to I-496 east downtown exit. Continue on I-496 to the Cedar/Larch and Pennsylvania exits. From this point, continue with the directions as given from the Detroit area above.

**From Saginaw/Bay City Area:** Follow I-75 south to I-69 west to 127 south to the I-496 west down exit. Continue on I-496 to the Cedar/Larch and Pennsylvania exits. From this point, continue with the directions as given from the Detroit area above.

**From the Jackson Area:** Follow 127 north to I-496 west down exit and continue on I-496 to the Cedar/Larch and Pennsylvania exits. From this point, continue with the directions as given from the Detroit area above.
RETURN this registration form and payment by FRIDAY, APRIL 15 to:

2005 Summit on Genomics
c/o Diversified Management Services
P.O. Box 423  Eaton Rapids, MI  48827  FAX: 517-663-5245

Faxed registrations are accepted to reserve a registration slot. Payment must be received by April 15 to confirm that registration. A parking pass and information on your confirmed work group will be mailed the week of April 18.

PLEASE COMPLETE BOTH SIDES OF THIS FORM.

FIRST NAME  LAST NAME  DEGREE

TITLE

ORGANIZATION

ADDRESS

CITY  STATE  ZIP CODE

TELEPHONE  FAX

E-MAIL ADDRESS

Payment Information

To reserve your seat at the Summit and help defray the cost of parking and refreshments, please submit a registration fee of $15 per person, payable by April 15. You will receive a parking voucher with your confirmation letter.

MAKE CHECK PAYABLE TO: Genomics Summit and mail to the above address.

☐ Check #_____________ in the amount of $15 is enclosed to reserve my seat.

☐ Please reserve my seat at the Summit. A check will be mailed by April 15.

☐ Please reserve my seat at the Summit. I require an invoice to issue payment.

☐ Summit Sponsor—No additional fee required beyond sponsorship donation.

☐ MDCH Staff or Session Facilitator/Scribe.

☐ I would like to participate in the Summit, but need the registration fee waived in order to attend. (You will be contacted by the management office.)

☐ I would like to apply for a travel subsidy. (Available to attendees traveling 130 miles or more each way. You will be contacted by the management office.)
Work Group Registration

Pre-registration is required to process your registration. Please indicate your first and second preference for your work group participation. Your assigned work group will be confirmed prior to the Summit. You are asked to attend the same work group both at 11:15 a.m. and 2:00 p.m.

Work Group A: Access to Genetic Services
Work Group B: Birth Defects Prevention
Work Group C: Cancer Genetics
Work Group D: Educating the General Public
Work Group E: Emerging Technologies and Treatments
Work Group F: Genes and the Environment
Work Group G: Genetic Testing and Laboratory Issues
Work Group H: Integrating Genomics in Chronic Disease Programs
Work Group I: Linking Families to Services
Work Group J: Expanded Newborn Screening
Work Group K: Transition Issues and Genetic Health Care for Adults

Special Requirements

☐ I require a vegetarian meal.
☐ I have a special dietary requirement:

☐ I have a physical requirement:

☐ I am interested in helping to sponsor the Summit. Please contact me with more information.

Inclusion of Name in Program Book

☐ YES, you may include my name and address in the Summit program book.
☐ NO, I do not want my name and address included in the Summit program book.

POSTER SOLICITATION FORM

The Summit is inviting poster presentations on your research or activities related to any of the six core goals of the State Plan, Genetics Through the Life Cycle: Improving Health and Preventing Disease. (See page 3 of this brochure for a list of the core goals.) To submit a poster, please complete the information below and include an abstract on a separate sheet. The abstract should include the title, authors and their affiliations, and project description in no more than 150 words. The deadline for poster submissions is Friday, April 8. You will be notified of acceptance during the week of April 18.

Please complete the following information and submit this form with your poster description.

Author’s Name and Title

Organization

Telephone and E-mail address

Title of Poster

The content relates to State Plan Goal(s) # ________________ (See page 3 for the list of core goals and use the numbers to respond to this question.)

Contact Person for this Poster (if different than author)

Telephone and E-mail address
The Michigan Department of Community Health is establishing the Director’s Recognition Award to honor an individual or organization who has made a significant contribution to one or more of the State Genetics Plan core goals during the last two years. The award will be presented by Director Olszewski prior to lunch at the Summit on May 2.

You are invited to submit a nominee for the Director’s Recognition Award. You must complete this form in its entirety and return it to the Summit management office as indicated below. The deadline for nominations is Friday, April 8.

**NOMINEE INFORMATION** (Information on person or organization being nominated.)

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**NOMINATOR INFORMATION** (Person submitting the nomination form.)

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Please describe why you are nominating this person or organization and include the core goal(s) to which they have contributed. (See page 3 for a list of the goals.) You may submit an additional sheet of paper.
Register by Friday, April 15, 2005, to ensure your seat at the Summit!