

CAPABILITY 2009

Irmgard Nippert



Manyeleti Game Reserve
Khoka Moya Camp, South Africa
25-30th March 2009

**CAPABILITY MID-TERM EVALUATION MEETING
LIMPOPO PROVINCE, SOUTH AFRICA**

27-29TH MARCH 2009

AGENDA

CAPABILITY 2009: PROF IRMA NIPPERT

CAPABILITY DEMONSTRATION PROJECT PROGRESS REPORTS

- 1. PROF RANDA RAOUF**
- 2. DR CRISTINA BARREIRO**
- 3. PROF JOERG SCHMIDTKE**
- 4. DR FLORIAN MEYER**
- 5. PROF ARNOLD CHRISTIANSON**

HEALTHCARE NEEDS ASSESSMENT REPORT: PROF ARNOLD CHRISTIANSON

IPTS (Seville) SURVEY

GENED DATA: PROF PETER NIPPERT

GENERAL DISCUSSION will take place after each topic

**Report from
the CAPABILITY
Co-ordination
Office**

Changes...

Co-ordination Office



Karina Bertmaring
Secretariat



Christoph Ries
IT & Communications
riesc@uni-muenster.de

**Report accepted
for the
1st reporting period
months 1 - 18**

Funding for the 2nd reporting period months 19 - 36

Timetable

2nd reporting period

see plan and status barchart

CAPABILITY Deliverables months 19-36

Deliverable No	Deliverable title	Due date	Delivery date
D11	Revised Model Approach	M14	M22
D14	Mid-term review demonstration project	M22	M22
D15	Demonstration project completed	M32	M32
D16	Demonstration project report	M33	M33
D17	Workshop III	M34	M34
D18	Model Approach Report: completed	M36	M36
D19	Report available on CAPABILITY website	M36	M36
D20	International dissemination of report	M36	M36

CAPABILITY Workpackages months 19-36

- **(WP6) Validate the model approach for adaptability to local health care needs in different settings (demonstration project) in defined areas**
- **(WP7) Consult different stakeholders on demonstration project outcomes (Workshop III)**
- **(WP8) Develop a model approach for test evaluation and capacity building based upon the outcomes of the demonstration project and stakeholder consultation.**
- **(WP9) Disseminate model approach to defined target audiences**

Function of the “mid-term” meeting...

Background

- CAPABILITY will develop a small scale project to assess the applicability of capacity building recommendations at 4 target sites in participating countries, based upon priorities recommended by the needs assessment survey

Background

- **Potential capacity building recommendations:**
 - **patient/parent or community education**
 - **networking of services to improve referral**
 - **educating primary health care providers in a defined public health setting, etc.**

- **The demonstration project will be conducted at four different study sites in order to allow evaluation of adaptability and transferability of the model.**
- **Participants 5, 6, 7 will conduct the project at defined settings in their countries, participant 3 at a defined site in the EU.**

- **The demonstration projects will be submitted to a mid-term audit organised by participant 5 (participant 2 and 4 will attend in the review).**
- **Participants 3 and 5, with assistance from participants 1, 6 and 7, will be responsible for the delivery of the outcome report of the demonstration project.**

Function of the “mid-term” meeting

The demonstration project will be subjected to a mid-term audit to be organised by participant 5 in co-operation with the other members of the Working Group, to allow for adjustments.

The March of Dimes Global Programs (MoD) has agreed to participate in the audit process from a global perspective and will act as an independent evaluator of the project.

The outcome of the demonstration project will be presented to stakeholders, including parent/patient organisations, observers from New Member States and third countries, policy makers at Workshop III.

**Dissemination of
knowledge
and raising
public awareness...**

Upcoming meetings

European
**HUMAN
GENETICS**



Conference 2009

Vienna, Austria

May 23 - 26, 2009

**Austria Center Vienna
Bruno Kreisky Platz 1,
1220 Vienna, Austria**

<http://www.eshg.org/eshg2009/>

Flyer for ESHG meeting

**Joint meeting with the
Global Partnership for Perinatal
Health Network (GPPN):**

**Shangri-La area,
Yu-an province, China**

week of August 20th, 2009



4th International Conference on BIRTH DEFECTS & DISABILITIES IN THE DEVELOPING WORLD

4 - 7 October, 2009
New Delhi, India

Translating Research into
Cost-effective Services for Care and Prevention



www.icbd2009.com

Topics of the Conference

- Health Care Delivery in Developing countries
- Preterm Birth – Current status & Future prospects
- Use of Birth Defect Surveillance For Research and Prevention
- Preventive Strategies for Birth Defects & New Born Screening
- Prevention of Known Teratogen Exposures & Their Prevention
- Global Networks for the Prevention of Birth Defects & Preterm Birth
- Folic acid & Other Micro-nutrients in Birth defects
- Perinatal Infections, Diagnosis, Management & Vaccines
- Hemoglobinopathies – Global perspective on Control
- Genomic Research in Birth Defects
- Affordable Diagnostics & Treatments in Dev. Countries
- Role of Parent / Patients organizations
- Ethics & Legal issues re Disabilities, Have we done enough?
- Models of Care & Rehabilitation in Developing World

CME's - 4th Oct., 2008 (Sunday)

- Parent/ Patient organizations
- Mental Retardation
- Neuromuscular disorders
- Thalassemia and Sickle cell disorders
- Genetics for Physicians/ Pediatricians

Registration Fee

Category	Early bird till 31st March '09		Go to 31st July '09		Go to 31st Aug '09		On spot	
	USD	INR	USD	INR	USD	INR	USD	INR
Delegate	750	14,200	800	16,000	900	18,000	750	23,000
Accompanying Delegate	280	6,200	280	6,000	200	6,800	280	8,800
Student / Parent	170	3,200	170	3,800	200	5,800	280	11,000
Child	US \$ 100 / INR 4,800		US \$ 125 / INR 5,800					
Post-conference			US \$ 75 / INR 3,200					

Committee members

Executive Committee:

Ishwar Verma, India
Michael Katz, USA
Ratna Puri, India
Coleen Boyle, USA
Eduardo Castilla, Brazil
Arnold Christianson, South Africa
James Hanson, USA
Christopher Howson, USA
Alistair Kent, UK
Li Zhu, China

Programme Committee:

Jose Cordero, USA
Suzhat Fuchaneon, Thailand
Madhulika Kabra, India
Pierpaolo Mastrolacovo, Italy
Jeffrey Murray, USA
Ima Nippert, Germany
Carmencita Padilla, Philippines
Ysbrand Poortman, Netherlands
Jai Rup Singh, India
David Weatherall, UK

For Further information and participation contact:

Conference Organizer

Ishwar Verma
Sr. Consultant and Chairman
Dept. of Genetic Medicine Room No. 25
Sir Ganga Ram Hospital, Rajinder Nagar
New Delhi - 110060, INDIA
Tel: +91-11-25661767, 42251382
Fax: +91-11-42251004
Email: icbd@icbd2009.com,
ishwar@icbd2009.com
Website: www.icbd2009.com

Michael Katz
Secretary, Executive Committee
Senior Vice President for Research
and Global Programs
March of Dimes Foundation
1275 Manhattan Avenue
White Plains, NY 10605, USA
Tel: + 914 987 4955
Fax: + 914 987 4980
Email: mkatz@research.dimes.com

Official Conference Managers

Conference Secretariat
Placit by Creative Travel
Creative Travel Pvt. Ltd.
Creative Plaza, Mansarovar, Malviya
New Delhi - 110021 INDIA,
Tel: +91-11-26572267/68 Fax: +91-11-26585586, 26885704
Email: icbd@icbd2009.com, rahul@creative@icbd2009.com
Website: www.placit-india.com



NETWORKS PLENARY

New Delhi, October 2009

90 minutes

Introductory remarks	Moderator 1	5 min
Reports of CAPABILITY Network members*		
	Arnold Christianson (South Africa)	10 min
	Randa Raouf (Egypt)	10 min
Reports of GPPHN members*		
	Nanbert Zhong (China)	10 min
	Carmencita Padilla (Philippines)	10 min
	Khalid Yunis (Lebanon)	10 min
	Roberto Giugliani (Brazil)	10 min
Presentation of Draft Recommendations And Next Steps for Building Global Networks	Moderator 2	10 min
Q & A and General Discussion		15 min

* Reports will describe activities being conducted but, more importantly, also focus on discussion of the special benefits and constraints of working within a network



CAPABILITY Workshop
Trolleholm, Sweden
November 30th – December 4th, 2009

Cooperation...



EuroGentest

Genetic Testing in Europe

Network for test development
harmonization, validation and
standardization of services

Units 3 + 6



Joint survey

Collaboration with MoD Global Programs

Joint meetings

- **Shangri-La**
- **New Delhi**

Publications

→ Special issue of the
Journal of Peking University
(Health Science)
for the month July-August 2009
together with the GPPHN

CAPABILITY has been invited by
the editor (Nanbert Zhong) to
submit articles



Thank you for your attention!