

Meeting Our Children's Needs: Community-Driven HIV/AIDS Research Partnership

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Introduction to IMPAACT

International Maternal Pediatric Adolescent AIDS Clinical Trials Network

(Formerly Pediatric AIDS Clinical Trials Group [PACTG])

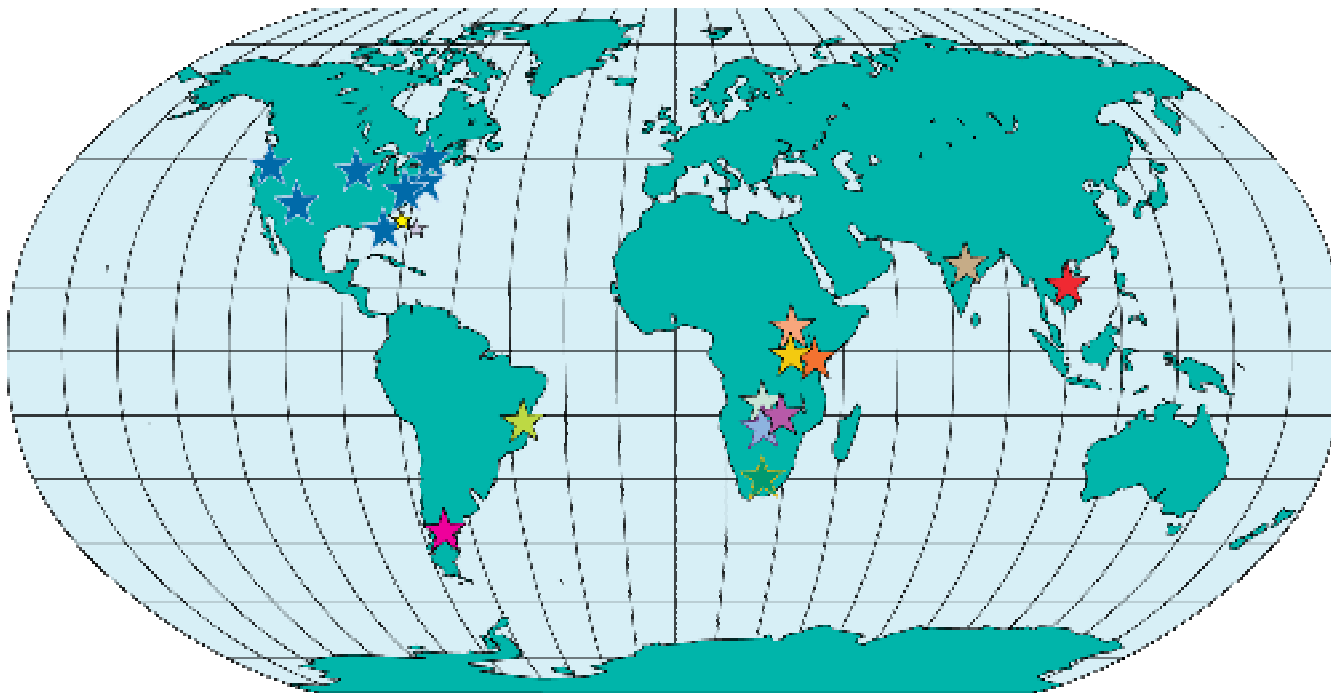
Mission

- To prevent and treat HIV in infants, children, adolescents and pregnant women domestically and internationally

One of six HIV/AIDS clinical trials networks funded by the National Institute of Allergy and Infectious Diseases (NIAID)



IMPAACT Sites



USA	Brazil	Malawi	Botswana	India
Bahamas	Argentina	Tanzania	South Africa	Thailand
Puerto Rico	Zambia	Zimbabwe	Uganda	

Source: François-Xavier Bagnoud Center at the University of Medicine and Dentistry of New Jersey (UMDNJ)





Community Advisory Board (CAB)

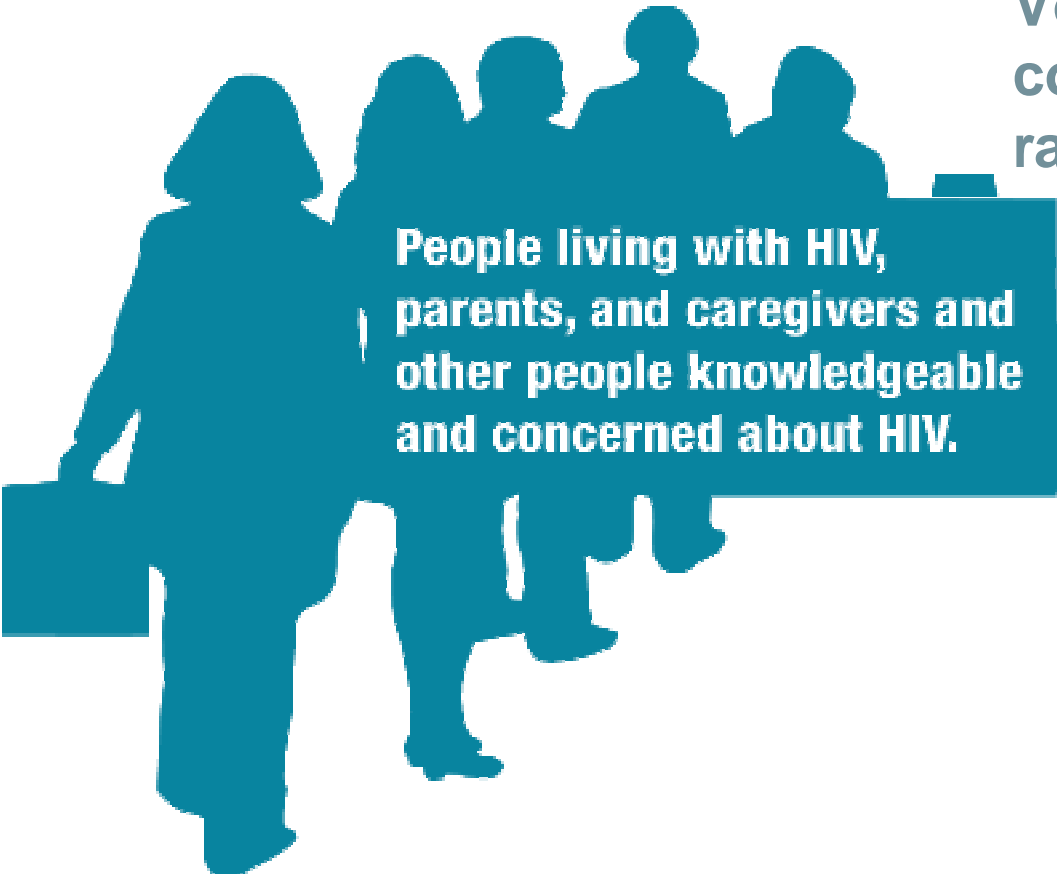
- A group of people from the local community who
 - Bring community concerns about the research to the research team
 - Teach members of the community about research

Source: François-Xavier Bagnoud Center at the University of
Medicine and Dentistry of New Jersey (UMDNJ).



Who are CAB members?

Volunteers from the
community with broad
range of backgrounds



People living with HIV,
parents, and caregivers and
other people knowledgeable
and concerned about HIV.

Source: François-Xavier Bagnoud Center at the University
of Medicine and Dentistry of New Jersey (UMDNJ).





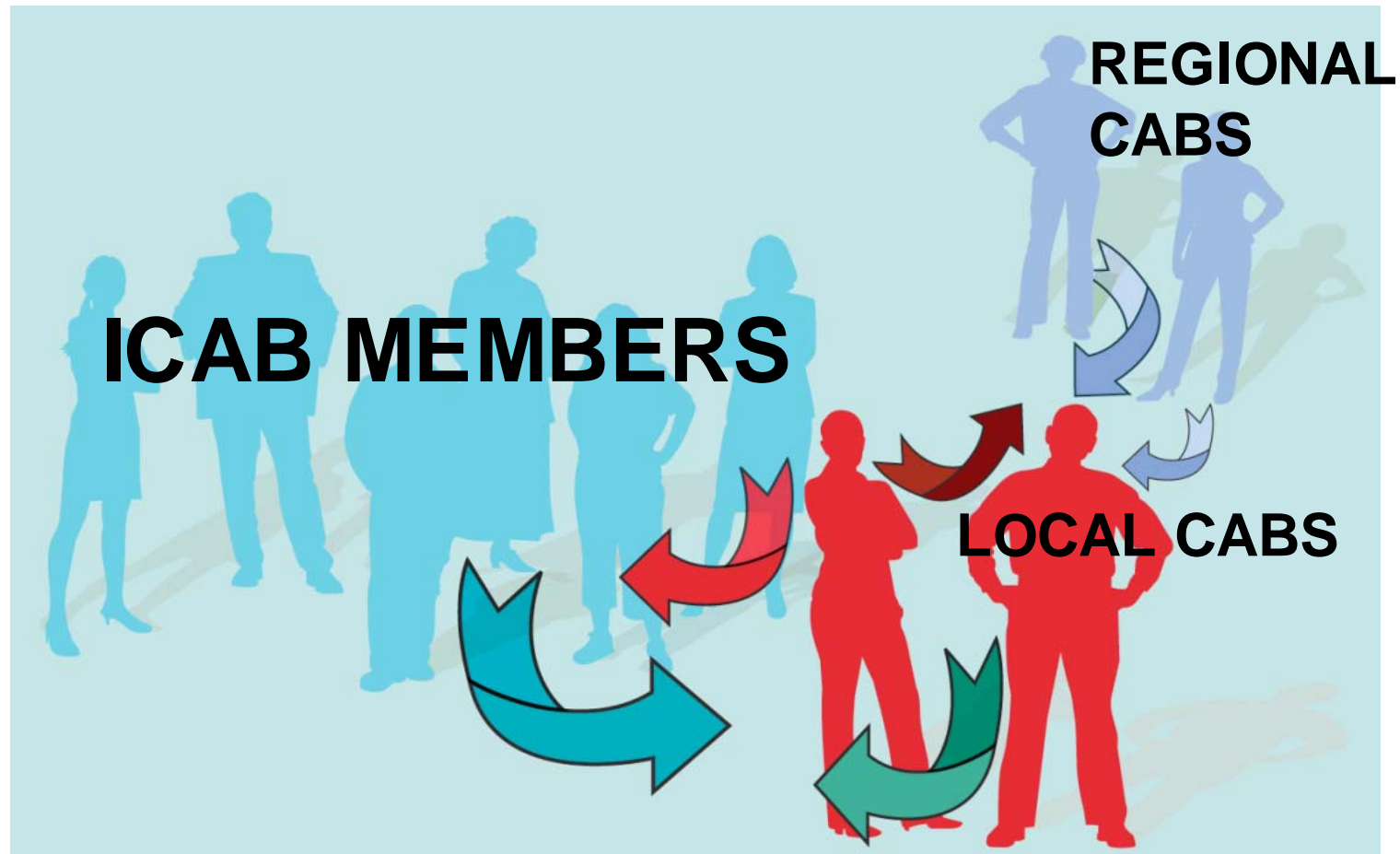
IMPAACT Community

- Direct Stakeholders:
 - HIV-positive women of child bearing age; pregnant women; parents, caregivers of HIV infected and affected babies, children and young people; and young people themselves.

- Indirect Stakeholders:
 - Affected people and others in the community including professionals.



IMPAACT Community



Source: François-Xavier Bagnoud Center at the University of Medicine and Dentistry of New Jersey (UMDNJ).



IMPAACT CAB Strategic Goal

To collaborate with researchers on behalf of the global community to achieve relevant, acceptable, and ethical research that focuses on the lives and issues of pregnant women, children, adolescents and families infected with or affected by HIV/AIDS.





Community Involvement in IMPAACT

IMPAACT CAB representatives join protocol teams to speak to the team about:

- The risks and potential benefits of the protocol
- The design of the study
- What is expected of participants who join the study
- Who can join the protocol and who is not allowed to join
- Whether the informed consent document is clear and understandable

Source: François-Xavier Bagnoud Center at the University of Medicine and Dentistry of New Jersey (UMDNJ).





Case Study: Families First

1990s – early 2000s:

- Families started voicing concerns about psychiatric issues among their HIV-positive children

- Are the causes
 - Neurological?
 - Mental?
 - Behavioral?
 - Environmental?
 - HIV infection?
 - Antiretroviral therapy?





Case Study: Challenges

Doctors' Response:

- Children with terminal/chronic illness have grown up being treated specially and have not learned to control their behaviors.
- It is related to parental depression or parental substance abuse.
- ADHD is so prevalent in our society.
- We didn't expect the children to live this long.

The doctors' focus was on keeping the child alive (breathing) longer.





Case Study: Challenges

Investigators' Response:

- Initially indicated there was insufficient science for psychiatric research question
- Denied PACTG CAB request for interactive on mental health issues of HIV infected children with NIH institutes and pharmaceutical companies
 - While working on this proposal, community members developed key contacts within the National Institutes of Health
 - PACTG CAB learned that institutes were already developing HIV/AIDS mental health research. Community members were not included in this process.





Case Study: Research Partnership

From advocacy to action:

- Feb. 2002: PACTG CAB developed first list of community scientific priorities, with psychiatric issues ranking in top three
- May 2002: Formally presented scientific priorities to PACTG Leadership
 - Including timeline for Leadership to address major priority areas
- Continued advocacy for community priorities and timeline





Case Study: Research Partnership

- Dialogue with network leadership & working group focused on complications on HIV disease and treatment
- Collaboration:
 - Utilized community's key contacts at National Institute of Mental Health (NIMH)
 - NIMH provided funding and contributed to study design
- Strong support from investigator who became study's lead researcher





Case Study: Results

IMPAACT P1055 “Psychiatric Co-Morbidity in Perinatally HIV-Infected Children and Adolescents”

- Community member on study team throughout protocol development
- 2005: IMPAACT P1055 opened to enrollment
- 582 participants enrolled at 29 sites across the U.S.
- Abstracts prepared on pain prevalence, psychotropic drug therapy and psychiatric symptoms
- New research partnership between NIH institutes (NIAID and NIMH)
- Future studies planned





IMPAACT Community Priorities

- The IMPAACT CAB updates the Community Scientific Priorities annually.
- 2007: 20 sites collected local scientific priorities to share with the research network.
- This community/research partnership ensures the development of studies that respond to global community priorities.





2006 Community Scientific Priorities

IMPAACT studies addressing Community Scientific Priorities:

- Interruption of transmission through breastfeeding
- Treatment (therapeutic) HIV vaccines
- Long-term follow-up
- Mental health issues in HIV-positive children
- Malnutrition and antiretroviral therapy
- Complications of HIV disease and treatment (cholesterol, bone mineral density)
- Immune Reconstitution Inflammatory Syndrome





Lessons Learned

- Families and communities may be first to notice health concerns/trends in their children
- Power of persistence and partnerships
- Strong allies are critical for moving community agenda forward
- Community representatives must be empowered to dialogue with researchers and leadership
- Community voices can result in action and shape pediatric HIV/AIDS research
- Community partnerships are essential for relevant, acceptable, and ethical research





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