



Easter Seals

Office of Public Affairs
1425 K Street, N.W.
Suite 200
Washington, DC 20005
202.347.3066 phone
202.347.7385 tty
202.737.7914 fax
www.easterseals.com

Easter Seals, Inc.
Public Comment on the Recommendations of the World Health Organization
Intergovernmental Working Group (IGWG) on Public Health, Innovation and
Intellectual Property – Submitted 30 September 2007

Easter Seals is a private, nonprofit organization dedicated to helping children and adults with disabilities and their families achieve health, independence, and full inclusion in community life. Each year, Easter Seals provides community-based services and supports to more than one million individuals in the United States. For most Easter Seals clients, access to appropriate medicines is critical to their health and quality of life.

Easter Seals is a member in good standing of the United States International Council on Disability, which is a member organization of Rehabilitation International. Easter Seals regularly participates in information exchange and missions with government and non-government interests beyond the borders of the United States, including with elected officials, public health personnel, health practitioners, and private individuals living in developed and developing nations.

Easter Seals appreciates the World Health Organization's goals in undertaking this IGWG effort, and fully supports increased access to needed medicines in developing countries and globally. Easter Seals is concerned that much of the discussion to date has been excessively focused on changing and generally weakening rules pertaining to intellectual property that will ultimately have a negative impact on the health and well-being of persons in the developed and developing world. With nearly 90 years of experience, Easter Seals promotes person-centered health care that helps individuals be informed and involved in decisions concerning their health, with unimpeded access to safe, appropriate, and affordable interventions that are available within and through a public health framework that optimizes roles for government, non-government organizations, and the private sector. Access and innovation are interwoven in our experience, because without access, innovation provides no benefit, and without innovation, access cannot achieve desired, increasingly better outcomes.

As the IGWG initiative advances, Easter Seals recommends the following:

- 1) Recognize and engage more fully the population for whom this effort is ultimately intended to benefit: patients, their families and their advocates. Easter Seals believes that the IGWG global strategy and plan of action will be strengthened by the active solicitation and consideration of the perspectives and recommendations of patients and those closest to them. A person-centered approach will lead to better, more lasting individual and public health outcomes, but it must be present from the onset of deliberation and decision-making. A phrase used within the disability community captures this sentiment: “Nothing about us without us.”**
- 2) Develop and promote improved strategies for public health that have application and merit in developing and developed countries so that all people receive the health-related interventions, education, and supports that they need to live full and healthy lives. The IGWG initiative is challenged by the complexity of public health, as intended and expressed worldwide. Easter Seals believes that too-narrow a focus on any one factor affecting access, such as drug pricing or patent strength, will limit the effectiveness of proposed solutions, and likely have an adverse impact on other valued aspects of global public health and health innovation.**

Easter Seals also believes that efforts to improve health in developing countries that are disproportionately affected by infectious disease and gaps in public health infrastructure should not be pitted against efforts in the developed world to address growing rates of chronic disease and age-related impairments. Ideally, IGWG can create strategies that are holistic, and that embrace all stakeholders, including patients and patient advocates, intergovernmental agencies, national and local governments, non-government organizations, civil society groups, corporations, and foundations. Each has a role to play that is important and interrelated. In the aggregate, these resources together will yield the best results for the IGWG and the world’s health. Strategies that define the problem and resulting solutions too simplistically will miss opportunities for promoting meaningful progress and may well undermine current practices that have successfully led to widespread gains in longevity and health.

- 3) Encourage the development and deployment of quality medical treatments, interventions, and delivery methods to promote improvements in public health in developing and developed nations. Easter Seals believes that the IGWG must proceed very carefully in prescribing reform of the incentive systems and supports that govern private and public investment in alleviating disease and disability. Immediate and sweeping reform of the pharmaceutical research and development system, for example, is not advisable, as it risks disruption of a investment, innovation, and application stream that has originated many highly beneficial treatments for conditions affecting developed and developing world populations alike, such as HIV/AIDS.**

Strategies that induce change in the current system by strengthening the contributions of the range of public and private sector interests have the best chance, with perhaps less risk, of yielding comprehensive improvements across the spectrum of public health infrastructure, innovation, and intervention. For its part, Easter Seals is eager to expand its participation in the exchange of information and best practices with counterparts in developing nations to promote health and independence for people with disabilities and chronic conditions and their families. Other NGOs and civil society groups are likely equally qualified and ready to contribute expertise and resources to advance solutions relevant to the IGWG. The potential impact of this low-risk interaction and mutual problem-solving across developing and developed nations should not be underestimated.

- 4) Assure that the research, treatments and interventions to improve public health in developing and developed nations are safe, reliable, and effective and delivered in a manner that supports access and appropriate use. Easter Seals believes that all people are entitled to be informed about and to receive health care, including medicines and assistive devices, that they can trust to address their individual health needs. To this end, the IGWG is urged to:**
 - a. support patent protections and oversight to ensure that research, development and manufacturing of medicines and devices meet international standards;**
 - b. support strong manufacturing and distribution controls that protect the public from receiving medicines, devices, and other interventions that are not what they claim to be, such as tainted or counterfeit drugs that contain inert or harmful ingredients that cannot provide the intended therapeutic benefit;**
 - c. support improvements in public health infrastructure, especially in resource-poor countries that often struggle with basic health needs (clean water, sanitation, nutrition), and where there is need to strengthen health care delivery systems and improve education and deployment of health personnel; and,**
 - d. support health education of persons seeking health care to improve their “health literacy,” so they better understand the basics of wellness, disease prevention and health promotion, are knowledgeable about their own health (and that of their family), and can effectively seek out and appropriately use medicines and other interventions.**

Easter Seals offers these comments for consideration in the hopes that people most effected by the work of IGWG, the users of health care in developing and

developed countries, still have an opportunity to participate more fully in the crafting of a global strategy and a plan of action that truly advances public health worldwide. Undue focus on loosening patent protections, guidelines for the manufacture and distribution of medicines, or any other single aspect of this complex system that collectively defines public health worldwide, will likely have an unnecessary and detrimental impact on health innovation and access in the developing world and possibly globally. Please consider the IGWG charge and resulting solution strategies in a broader, more holistic manner, targeting ways to increase research and development of treatments for infectious disease, while also addressing fundamental issues such as insufficient government spending on public health and health care delivery systems, inadequate preparation and support of the health care workforce, generally weak systems of health regulation and management, and the pervasive, undermining impact of poverty on the building blocks of public health, such as a lack of clean drinking water, poor sanitation systems, and low health literacy. Look also for strategies that will enhance the ability of developing nations to engage in research and development of therapeutic interventions, participate in clinical trials, interpret and utilize research results, and produce and distribute reliable, high-quality medicines and devices.

In addition to the infrastructure needs mentioned earlier, Easter Seals believes that new strategies must implement best practices and quality assurance through training for health personnel to ensure safety and effective treatment of persons participating in clinical trials or simply seeking care. In all these areas, prevention needs to be a major focus for the reduction of infectious disease.

Easter Seals joins others organizations in recommending that WHO explore alternatives to promoting access to therapeutic interventions, including emerging examples of increased access to services and medicines in the United States resulting from innovative public-private collaboration, employer-based incentives, and reduction of market barriers. WHO is encouraged to identify and promote creative approaches and incentives for enhancing research development of medicines to combat tropical and neglected diseases, but not ignore “developed world diseases,” such as cancer, diabetes, and heart disease, that are also prevalent among developing world residents. These conditions are universal and efforts to find and implement effective treatments should be universally sought and applied. With the ease and speed of air travel, even tropical diseases and those typically associated with the developing world are less localized than before, so strategies developed by WHO might foster an understanding of shared risk, and insodoing, generate greater global interest in effective medical intervention.

On behalf of Easter Seals, Inc., thank you for this opportunity to contribute comments and recommendations to the Intergovernmental Working Group on

Public Health, Innovation, and Intellectual Property. Easter Seals looks forward to participating further in the development and implementation of a global strategy and plan of action on behalf of persons with disabilities and chronic conditions and their families in the United States and throughout the world.

Very best regards,

**Randall L. Rutta
Executive Vice President, Public Affairs
Easter Seals, Inc.**

**E-Mail: rrutta@easterseals.com
Telephone: (202) 347-3066
FAX: (202) 737-7914**