

Primary Prevention of Rare Diseases

ICORD meeting October 2014

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NZ Organisation for Rare Disorders

Folic Acid fortification of food

- Very safe and effective in preventing Spina Bifida and Anencephaly
- Part genetic and part environmental
- Two-thirds of cases are preventable with Folic Acid fortification of a staple food
- 2009 mandatory fortification of bread cancelled in New Zealand
- Public confidence undermined - a deliberate food safety fear campaign by bakers

CENTERS FOR DISEASE CONTROL

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MMWR

*Recommendations
and
Reports*

MORBIDITY AND MORTALITY WEEKLY REPORT

**Recommendations for the Use of
Folic Acid to Reduce the Number
of Cases of Spina Bifida and
Other Neural Tube Defects**

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U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Public Health Service
Centers for Disease Control
Atlanta, Georgia 30333



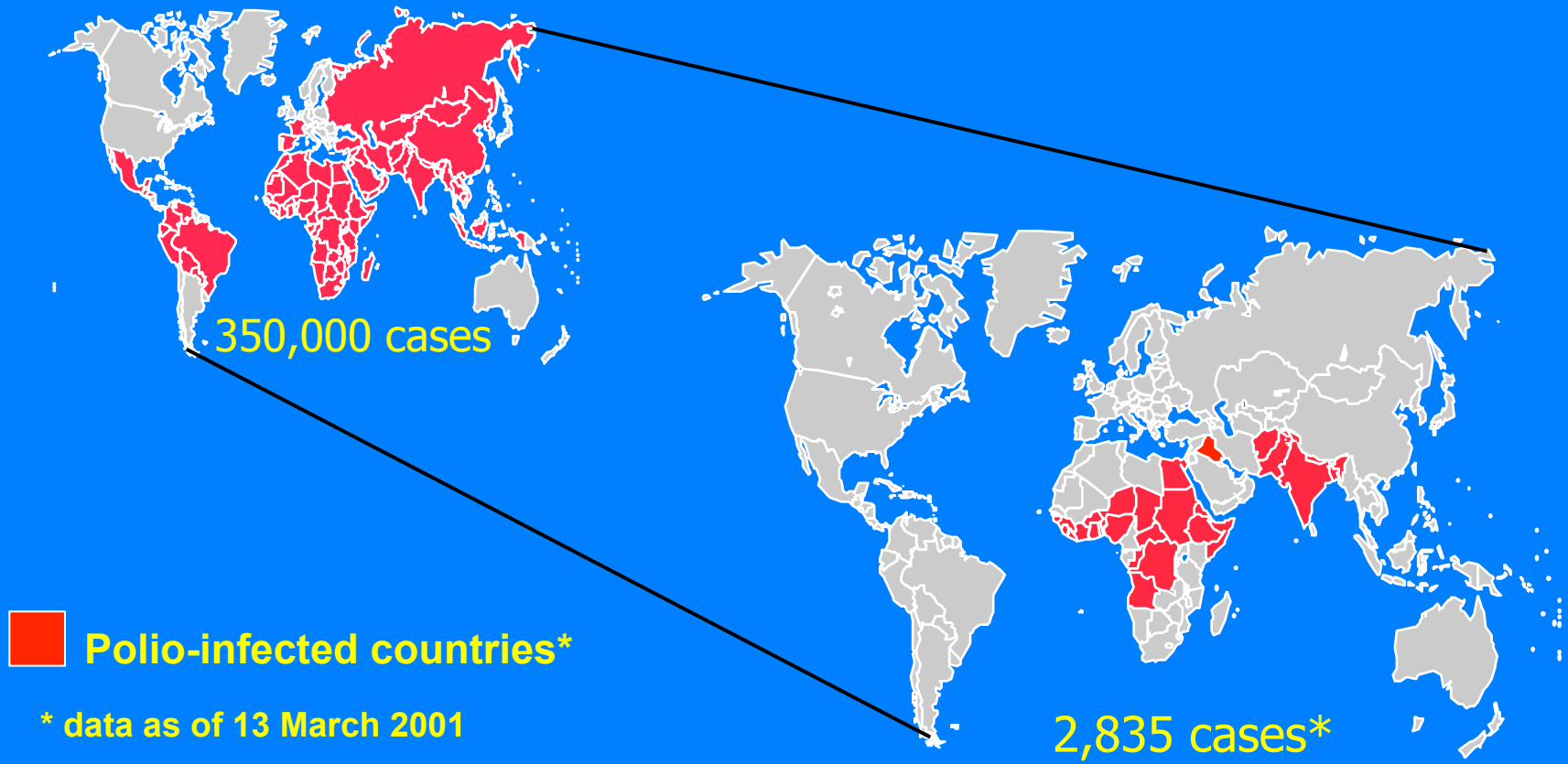
CDC
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AND PREVENTION

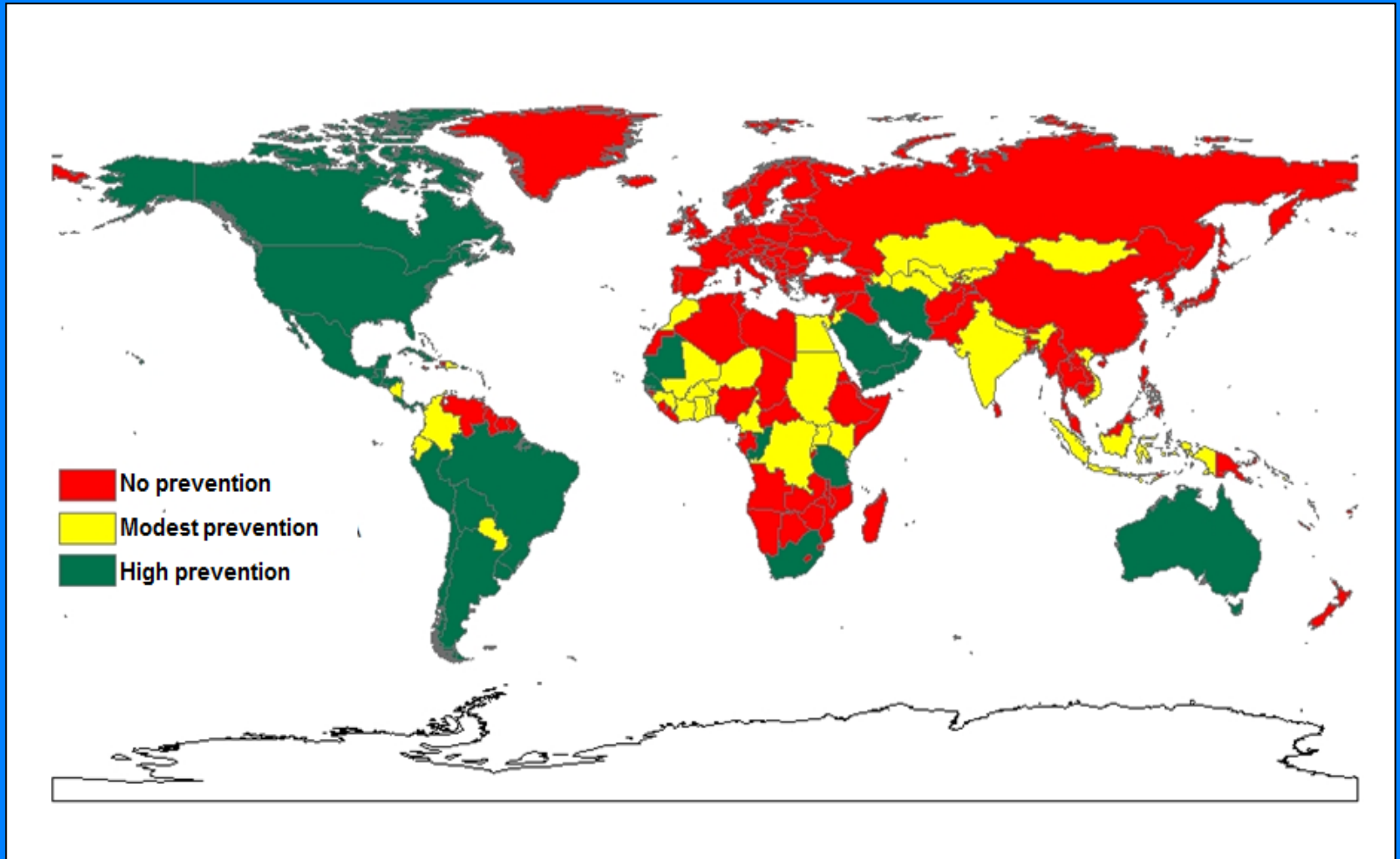
September 11, 1992

22 years ago

Polio Eradication Progress 1988-2000



Spina Bifida Prevention 2012



Compare this inaction on Folic Acid to efforts over thalidomide

- estimate of the number of children damaged by thalidomide - mostly Europe - 10,000 total.
- Un-prevented global annual toll for spina bifida and anencephaly is 18 times as large as the damage done by thalidomide - usually viewed as one of the worst human tragedies.

Statistics on costs of NTDs

- 180,000 un-prevented cases
- 50/50 Anencephaly and Spina Bifida
- 90,000 preventable deaths/year
- 90,000 seriously disabled/year
- Hospital costs NZ\$1 million each - age 20
- NZ\$90 Billion/year (B = 1,000 million)
- Euro 55 Billion/year

A decision-making framework

- The challenge of making good public health decisions in the face of controversy
- All public health issues, including fluoride, seat belts, vaccines, bicycle helmets, are contested
- Strong medical and political leadership is needed
- Risks and benefits should be quantified

Sound ethical frameworks are needed

- There is a moral duty to act when there is clear evidence of preventable harm
- For folic acid and NTDs, imperative to note that status quo is not a benign state
- Taking no action produces harm
- Precautionary principle should be measured and adapted against this reality, rather than dominate policy

Alternatives to fortification

- Evidence shows that supplementation policies have minimal effects on incidence of NTDs
- Voluntary fortification is also a weak and failed approach
- Widespread fortification of a staple food is shown to be safe and effective
- Failure to fortify is a serious political and moral failure

Beauchamp and Childress

- This moral framework provides guidance on balancing risks and benefits
- Highly relevant to public health decisions
- Evidence of folic acid benefits strongly outweighs the unproven risk of harm
- Consequentialist frameworks would reach the same conclusion
- Decision makers need to recognise their moral responsibility to act

What next?

- Urgently review recommendations on folic acid for prevention of neural tube defects
- More than 4,500 affected pregnancies per year in Europe demands prompt action
- Failure to act does active harm

John, Judith, Timothy and Hollie

