

Galactosemia

A Cost Benefit Analysis of Newborn
Screening

Metabolic disorder

- Baby can't break down galactose
- Mortality
- Brain damage
- Symptoms
- Liver, vomiting, anemia, bleeding, infection

Why is it hard?

- Rare
- Clinical diagnosis is slow
- Expensive to diagnose

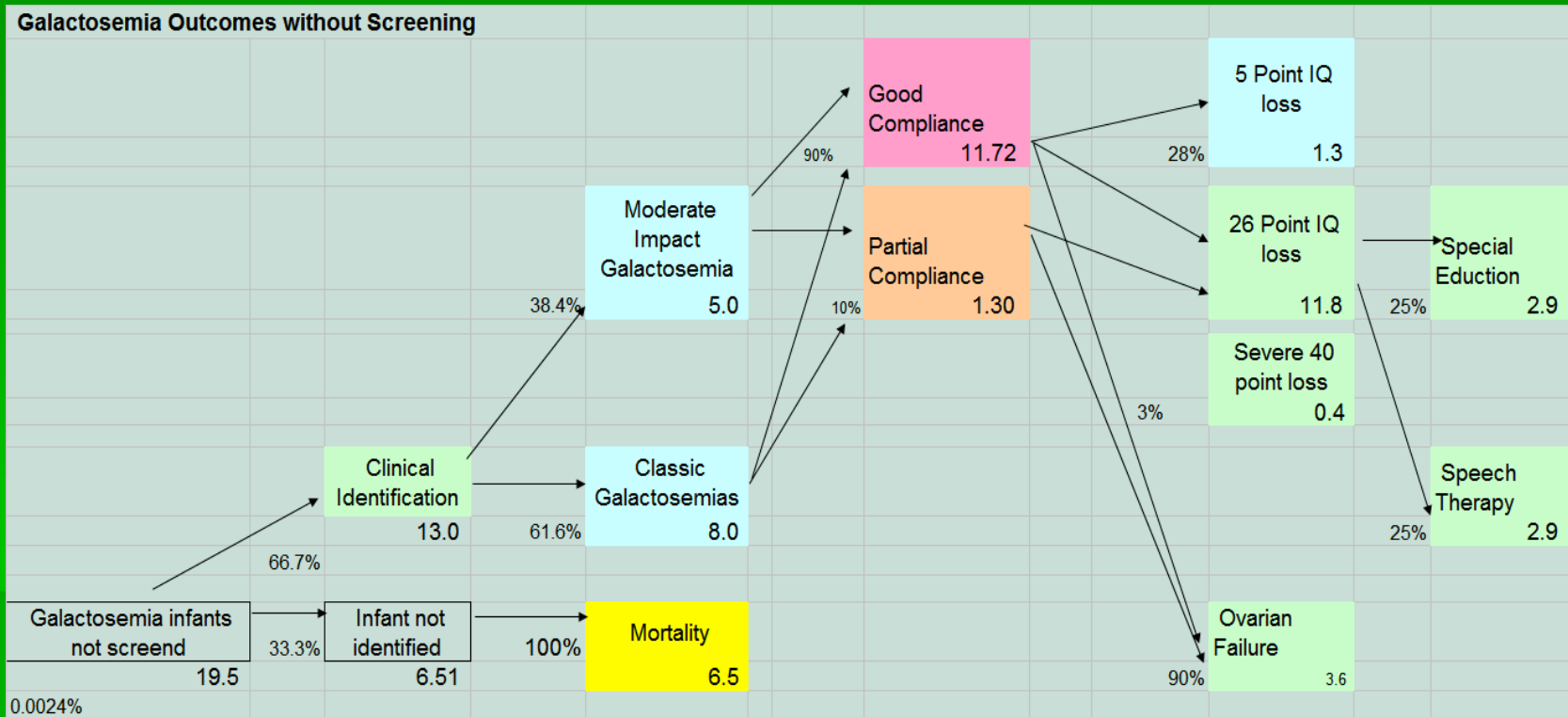
Solutions

- Blood spot testing
- Soy formula
- Lactose removed from the diet

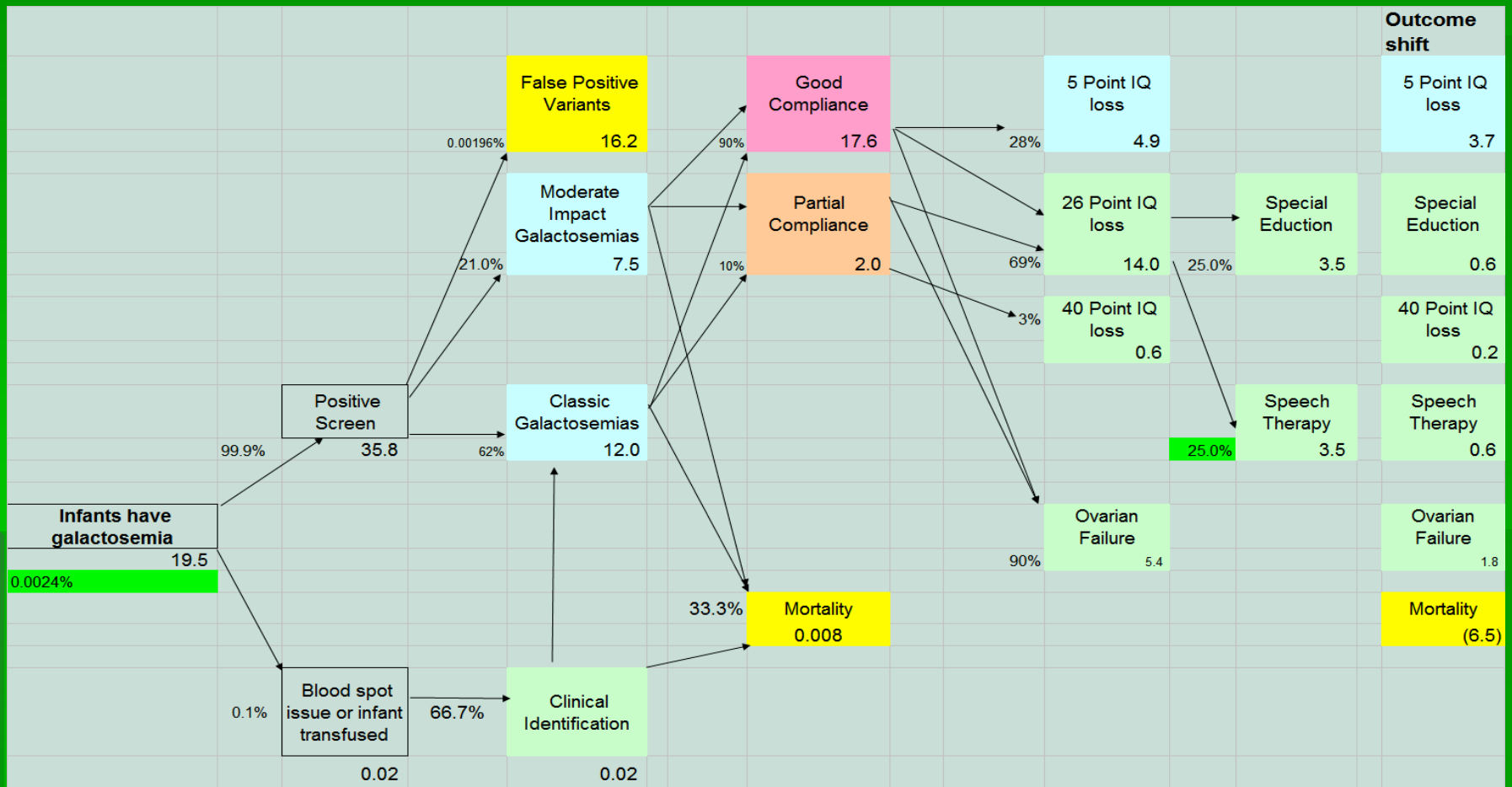
Downsides to Cure

- Ongoing treatment costs
- Q188R - severity
 - Micro deletions
 - Entire
- Brain damage continues
- Uterine failure

Medical outcome model



With screening



Model IQ outcomes

- Categories out of the range
 - 28% - 5 point IQ loss
 - 69% - 25 point IQ loss
 - 3% - 40 point IQ loss

Economics

- Value of QALYs saved
- Clinical diagnosis
- Cost of disorder
- Cost of compliance
- Cost of testing

Estimating Net Benefits		Expected Value
Gain		
Mortality avoided and value of QALYs	(6.5040)	\$ 18,753,392
Reduced cost of clinical Identification	19.5	\$ 254,036
Cost		
Foregone income and special Education		
Mild IQ Loss	3.68	\$ (314,509)
Significant IQ Loss	0.55	\$ (156,554)
Significant IQ Loss and Speech Therapy	0.55	\$ (372,475)
Severe IQ Loss	0.61	\$ (623,609)
Ovarian Failure	1.80	\$ (32,702)
Cost of effort required for food sorting	6.50	\$ (412,036)
Cost of monitoring tests	6.50	\$ (59,016)
Follow up test	6.50	\$ (2,971)
Cost of clinical program (share)	6.50	\$ (398,758)
Cost of Newborn Screening	6.50	\$ (2,036,479)

10 year impact

- Net of \$14.5 million
- Net without mortality -\$4 million
- Cost per QALY \$22 thousand
- Possibly the gain is greater in the UW program