Insights into NIH Funding of Hydrocephalus Research

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Chairman, Hydrocephalus Association
Public Funding Landscape

• Totals, Categories, Institutes and Types
• Trends over time
• Discussion
Method

• Searched RePORTER with keyword “hydrocephalus” over period
• Reviewed all abstracts for relevance
  – Checked edge cases with research advisors
• Consulted NIH regarding any gaps / questions
• Categorized scientific approach
• Tabulated, charted and analyzed results in XL
Total Spending 2002-2011

- NIH with stimulus: $54,056,677
- ARRA funding portion: $2,503,534
- Funding less ARRA: $51,553,143*
- 59 grantees received 66 unique awards
- Only one hydrocephalus PA exists
  - There is also one NICHD brain development PA that is very applicable

* NINDS does not include ARRA funding in its portfolio analysis
## NIH Hydrocephalus Spending by Category

<table>
<thead>
<tr>
<th>Category</th>
<th>2002-2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>Basic Science</td>
<td>$9,088,014</td>
</tr>
<tr>
<td>CSF dynamics</td>
<td>$4,896,398</td>
</tr>
<tr>
<td>Clinical (patient-based)</td>
<td>$25,117,186</td>
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<tr>
<td>Cognitive-behavioral</td>
<td>$1,843,638</td>
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<tr>
<td>Shunt device development</td>
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<tr>
<td>Other device development</td>
<td>$2,929,013</td>
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### Bar Chart

- **Basic Science**: $9,088,014
- **CSF dynamics**: $4,896,398
- **Clinical (patient-based)**: $25,117,186
- **Cognitive-behavioral**: $1,843,638
- **Shunt device development**: $9,935,552
- **Other device development**: $2,929,013
NIH Hydrocephalus Spending by Institute

- NINDS: 220,000,000
- NICHD: 2,400,000,000
- NIBIB: 2,000,000
- NIA: 1,000,000
- NIMH: 1,000,000
- OD: 1,000,000
- NCRR: 1,000,000
- NHLBI: 500,000
- NIAID: 100,000
- NIDDK: 500,000
- NIEHS: 300,000
## Institutions Awarded > $1 MM

<table>
<thead>
<tr>
<th>Institution</th>
<th>Award Amount</th>
<th>Project Focus</th>
</tr>
</thead>
<tbody>
<tr>
<td>GEORGE WASHINGTON UNIVERSITY</td>
<td>$7,145,134</td>
<td>MOMS</td>
</tr>
<tr>
<td>CHILDRENS HOSPITAL OF PHILADELPHIA</td>
<td>$5,667,592</td>
<td>MOMS</td>
</tr>
<tr>
<td>UNIVERSITY OF CALIFORNIA SAN FRANCISCO</td>
<td>$5,002,538</td>
<td>MOMS+ Training</td>
</tr>
<tr>
<td>VANDERBILT UNIVERSITY</td>
<td>$4,276,221</td>
<td>MOMS</td>
</tr>
<tr>
<td>NATIONAL INSTITUTE OF ENVIRONMENTAL HEALTH SCIENCES</td>
<td>$3,882,788</td>
<td>Basic Science on genes and brain development</td>
</tr>
<tr>
<td>UNIVERSITY OF CALIFORNIA LOS ANGELES</td>
<td>$2,379,118</td>
<td>Shunts / ICP</td>
</tr>
<tr>
<td>NEURODX DEVELOPMENT, LLC</td>
<td>$2,306,402</td>
<td>Shunts</td>
</tr>
<tr>
<td>CLEVELAND CLINIC LERNER COL/MED-CWRU</td>
<td>$2,197,334</td>
<td>CSF Dynamics</td>
</tr>
<tr>
<td>AFFINERGY ,INC</td>
<td>$2,083,120</td>
<td>Shunts</td>
</tr>
<tr>
<td>NEW YORK UNIVERSITY SCHOOL OF MEDICINE</td>
<td>$1,998,577</td>
<td>Clinical Core for Longitudinal Study (NPH tracked otherwise minor)</td>
</tr>
<tr>
<td>INFOSCITEX CORPORATION</td>
<td>$1,461,623</td>
<td>Shunts</td>
</tr>
<tr>
<td>MASSACHUSETTS GENERAL HOSPITAL</td>
<td>$1,424,228</td>
<td>Basic Science on CSF and Choroid Plexus</td>
</tr>
<tr>
<td>CHILDREN'S HOSPITAL MEDICAL CENTER CINCI</td>
<td>$1,358,206</td>
<td>CSF Dynamics with Imaging</td>
</tr>
<tr>
<td>H-CUBED, INC.</td>
<td>$1,326,417</td>
<td>Shunts</td>
</tr>
<tr>
<td>RHODE ISLAND HOSPITAL</td>
<td>$1,275,060</td>
<td>Basic and CSF Dynamics</td>
</tr>
<tr>
<td>UNIVERSITY OF UTAH</td>
<td>$1,206,548</td>
<td>Clinical (HCRN) , Training, Conference</td>
</tr>
<tr>
<td>UNIVERSITY OF MIAMI SCHOOL OF MEDICINE</td>
<td>$1,168,695</td>
<td>Basic and Cognitive</td>
</tr>
<tr>
<td>UNIVERSITY OF CHICAGO</td>
<td>$1,152,191</td>
<td>Cognitive</td>
</tr>
</tbody>
</table>
### Spending by Grant Types

<table>
<thead>
<tr>
<th>Grant Type</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research Projects</td>
<td>$15,744,180</td>
</tr>
<tr>
<td>SBIR-STTR</td>
<td>$10,055,385</td>
</tr>
<tr>
<td>Research Centers</td>
<td>$2,152,830</td>
</tr>
<tr>
<td>Career; Training; Individual;</td>
<td>$2,278,380</td>
</tr>
<tr>
<td>Intramural Research</td>
<td>$3,882,788</td>
</tr>
<tr>
<td>Clinical Trials</td>
<td>$22,045,944</td>
</tr>
</tbody>
</table>

Series 1
Overall Funding Analysis

• Total funding is low based on prevalence / burden compared to other conditions over last four years -- $30M over four years v.
  – Parkinson’s Disease: $629M
  – Epilepsy: $559M
• MOMS trial is nearly 50% of expended funds
• Devices take second place with 24% of funds
• Limited training / career awards
• NINDS and NICHD are the only “players”
Total NIH Hydrocephalus Spending
2002-2011
NIH Hydrocephalus Funding with MOMS Differentiated

Millions

- MOMS
- Other

Years:
- 2002
- 2003
- 2004
- 2005
- 2006
- 2007
- 2008
- 2009
- 2010
- 2011
NIH Hydrocephalus Spending by Institute Over Time

- NINDS
- NICHD
- NIBIB
- NIA
- NIMH
- OD
- NCRR
- NHLBI
- NIAID
- NIDDK
- NIEHS
NIH Hydrocephalus Spending by Category

- Basic Science
- CSF dynamics
- Clinical (patient-based)
- Cognitive-behavioral
- Shunt device development
- Other device development

2002 to 2011 spending distribution by category.
Trend Analysis

• Funding declines due ARRA and MOMS wrap-up
• NINDS is assuming the leadership role in hydrocephalus funding
• SBIRs and Devices are the key new “program”
  – PA’s definitely drive scientific submissions
• Approximately four to seven NEW grants per year
  – Extrapolated from paylines, there are 27-47 new grant applications per year but...
  – More likely 15-20 based on SBIR paylines and grant mix
  – There are not many hydrocephalus researchers!
Discussion

• There have been no fundamental advances in years and you can see why!

• Need help in growing ecosystem
  • Difficult to study, significant public health cost but we aren’t doing enough. Need help getting scientists interested.
  • Basic Science, clinical research and careers appear under funded

• What should we fund?

• Potential areas of research that are broader than hydrocephalus but that would be leveraged
  – Brain injury, brain development, CSF disorders