

ALS ASSOCIATION ADVOCACY UPDATE

2023 ALS RESEARCH APPROPRIATIONS



WELCOME

CALANEET BALAS

President & Chief Executive Officer



2023 ALS ASSOCIATION SPONSORS



THANK YOU TO OUR 2023 GOLD LEVEL SPONSORS



2023 ALS ASSOCIATION SPONSORS

Apellis



WELCOME

FROM OUR BOARD OF TRUSTEES

NANCY LEAMOND

Chair, Public Policy Committee

The ALS Association Board of Trustees

ADVANCING OUR MISSION

NEIL THAKUR, Ph.D.

Chief Mission Officer

**By 2030 ALS will be
a livable disease.**

A rapid and fundamental
transformation in the ALS
experience, until we find cure.





What Livable Means

People with ALS will have a fundamentally different experience than they have today.



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- **Longer lives**
 - More life extending treatments
 - Access to effective care



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- **Improved quality of life**
 - Greater engagement and autonomy
 - Reduced physical, emotional and financial burden



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- **Longer lives**
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 - Access to effective care
- **Improved quality of life**
 - Greater engagement and autonomy
 - Reduced physical, emotional and financial burden
- **Preventing new cases of ALS**
 - Reduced risk for loved ones
 - Expanded genetic counseling and testing

How We Get There

- Find New Treatments & Cures
- Optimize Current Treatments & Care
- Prevent or Delay the Harms Associated with ALS



OUR TOOLS

- **Research:** Generate new knowledge to treat and end ALS
- **Care Services:** Access effective treatment, services and support
- **Advocacy:** Engage the government in research, care services, treatment and support

Advocacy can help transform the experience of ALS for everyone here today, and eventually end it.

WE NEED TO WORK TOGETHER



ALS ADVOCACY LANDSCAPE

MELANIE LENDNAL

Senior Vice President, Public Policy & Advocacy



MAKING ALS LIVABLE WHILE WE WORK TO CURE IT

FIND NEW TREATMENTS & CURES

\$150M for ALS Research at the National Institutes of Health

\$25M for the Rare Neurodegenerative Disease Grant Program at FDA and \$75M For Expanded Access Programs

\$80M for the ALS Research Program at Department of Defense

OPTIMIZE CURRENT TREATMENTS & CARE

\$150M for ALS Research at the National Institutes of Health

Faster Access to promising drugs, treatments, and therapies

Ensure health insurance coverage of all drugs, treatments, and therapies

Affordable access to drugs

Telehealth Accessibility

Promote and pass the ALS Better Care Act

PREVENT OR DELAY HARMS OF ALS

\$150M for ALS Research at the National Institutes of Health

\$15M for the ALS Registry and Biorepository at CDC

Prevent health insurance practices that increase cost of care

Prevent health insurance practices that delay proper treatment

Ensure persons w/ ALS can travel

Provide support to caregivers

Ensure Medicare patients can access affordable Medicare Supplemental Coverage

Insurance coverage for genetic testing

Protections against insurance discrimination



CONGRESSIONAL FUNDING IN THE ALS RESEARCH ECOSYSTEM

PAUL LARKIN, Ph.D.

Director, Research



THE ALS ASSOCIATION IS THE LARGEST PHILANTHROPIC FUNDER OF ALS RESEARCH

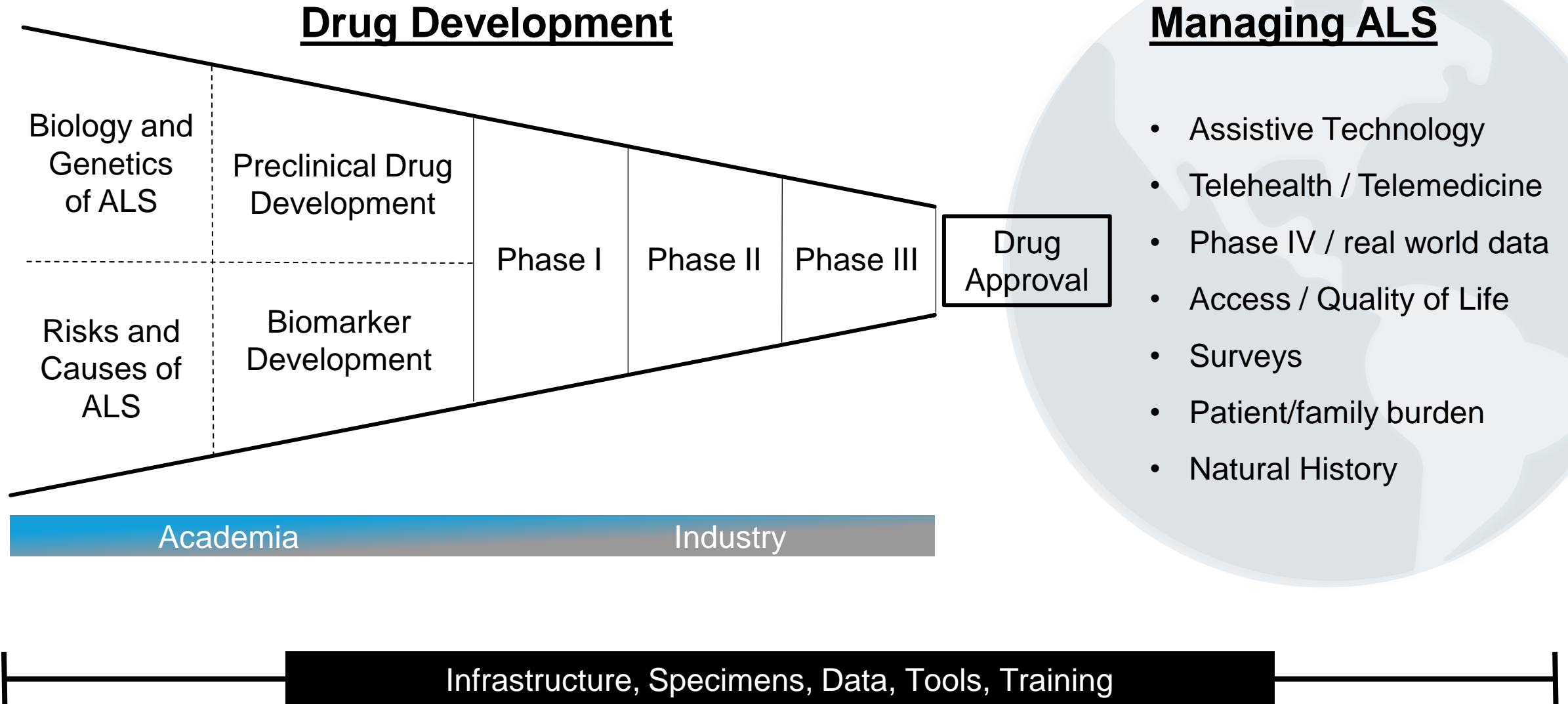
THE FUNDING PROCESS

- **Identify areas of need**
 - Work with our community to identify gaps and opportunities
- **Request and review applications**
 - Targeted requests for applications
 - Rigorous review process
- **Fund the best projects**
 - Around the world
 - In academic, industry, government or non-profit labs

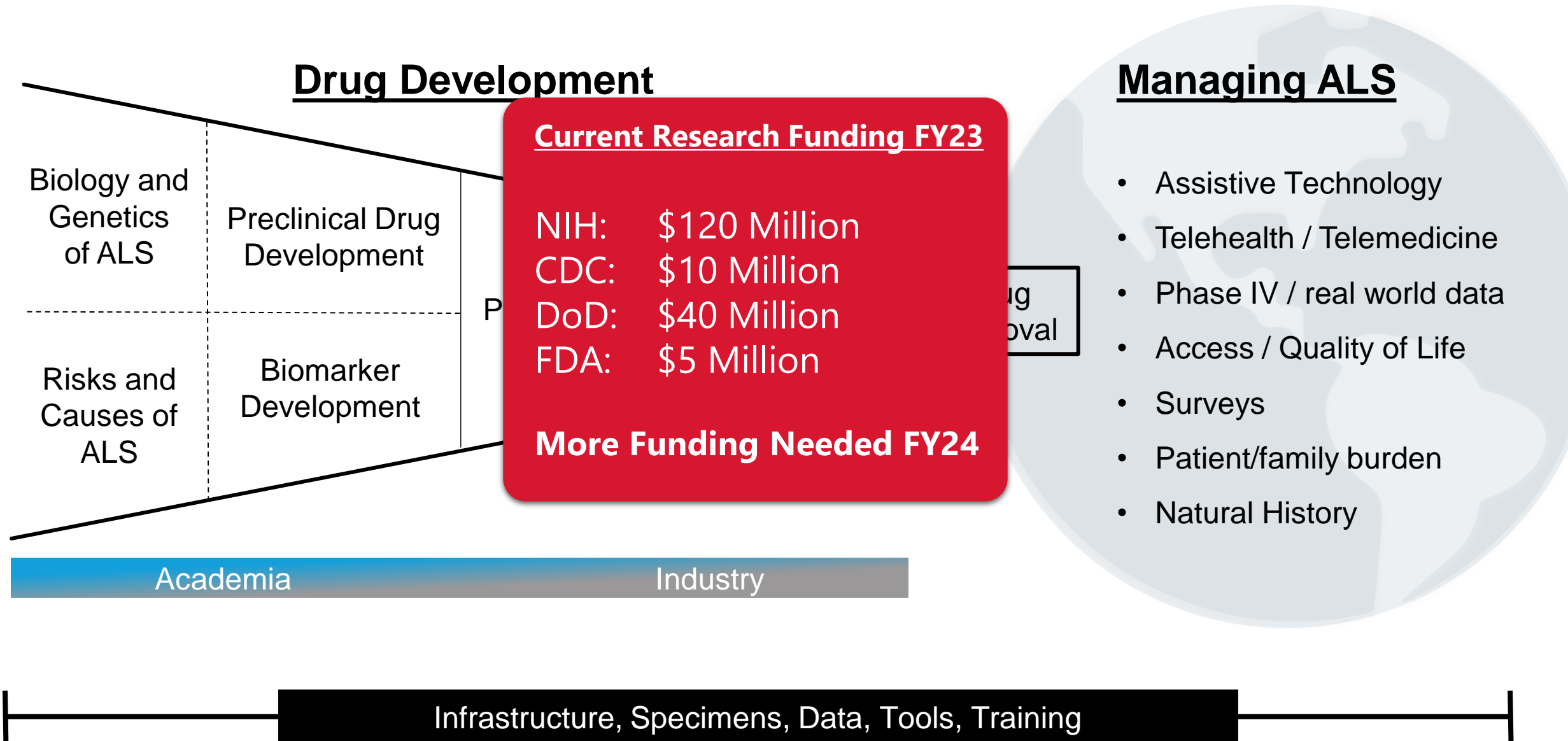
OUR 2022 RESEARCH FUNDING

- **Issued 7 Requests for Applications**
 - Variety of topics from infrastructure to drug development to prevention
- **Reviewed 245 applications**
 - From 18 countries, 29 states, Washington DC and Puerto Rico
- **Committed \$15 million to fund 59 new projects**
 - Projects span the entire ALS research ecosystem

ALS RESEARCH ECOSYSTEM



CURRENT CONGRESSIONAL FUNDING OF ALS RESEARCH



CURRENT CONGRESSIONAL FUNDING OF ALS RESEARCH - NIH

NIH: \$120M

Drug Development

Biology and Genetics of ALS

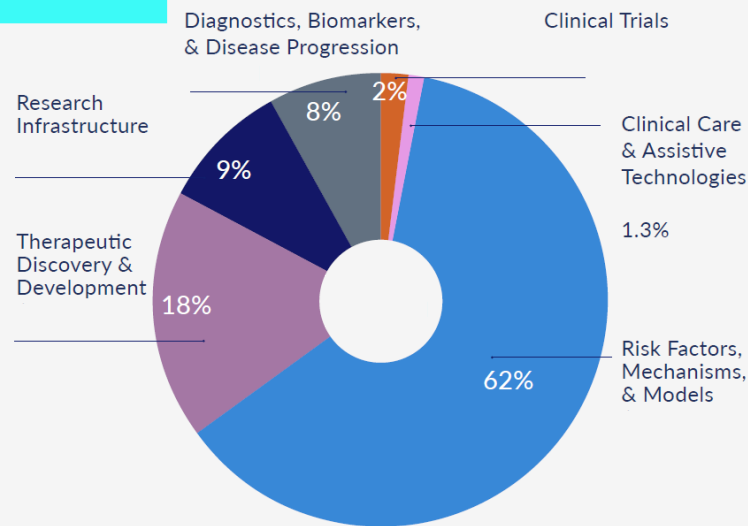
Preclinical Drug Development

Risks and Causes of ALS

Biomarker Development

Pha

FIGURE 6: NIH Funding of ALS Research



Source: Milken Institute (2022), using data from NIHReporter and Federal Reporter (2016-2020)

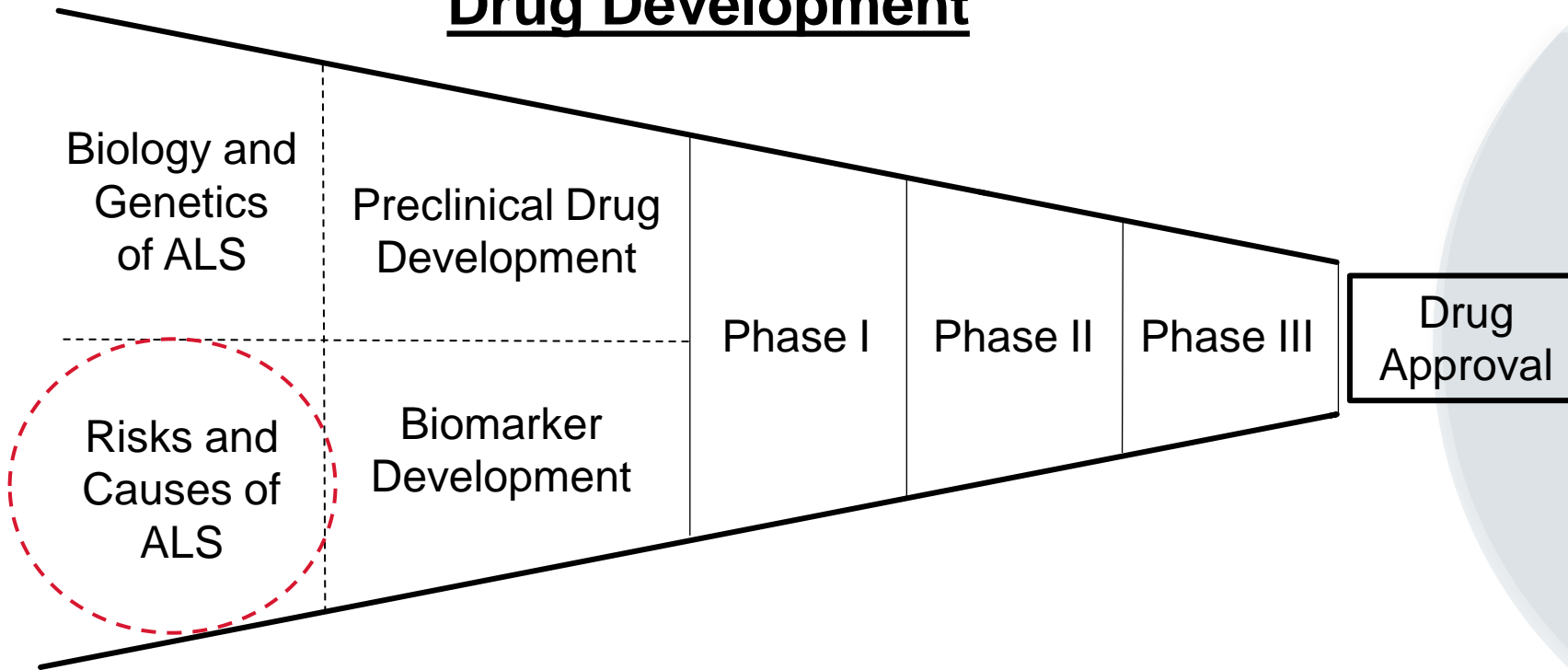
Managing ALS

- Assistive Technology
- Telehealth / Telemedicine
- Phase IV / real world data
- Access / Quality of Life
- Surveys
- Patient/family burden
- Natural History

Infrastructure, Specimens, Data, Tools, Training

CURRENT CONGRESSIONAL FUNDING OF ALS RESEARCH - CDC

Drug Development

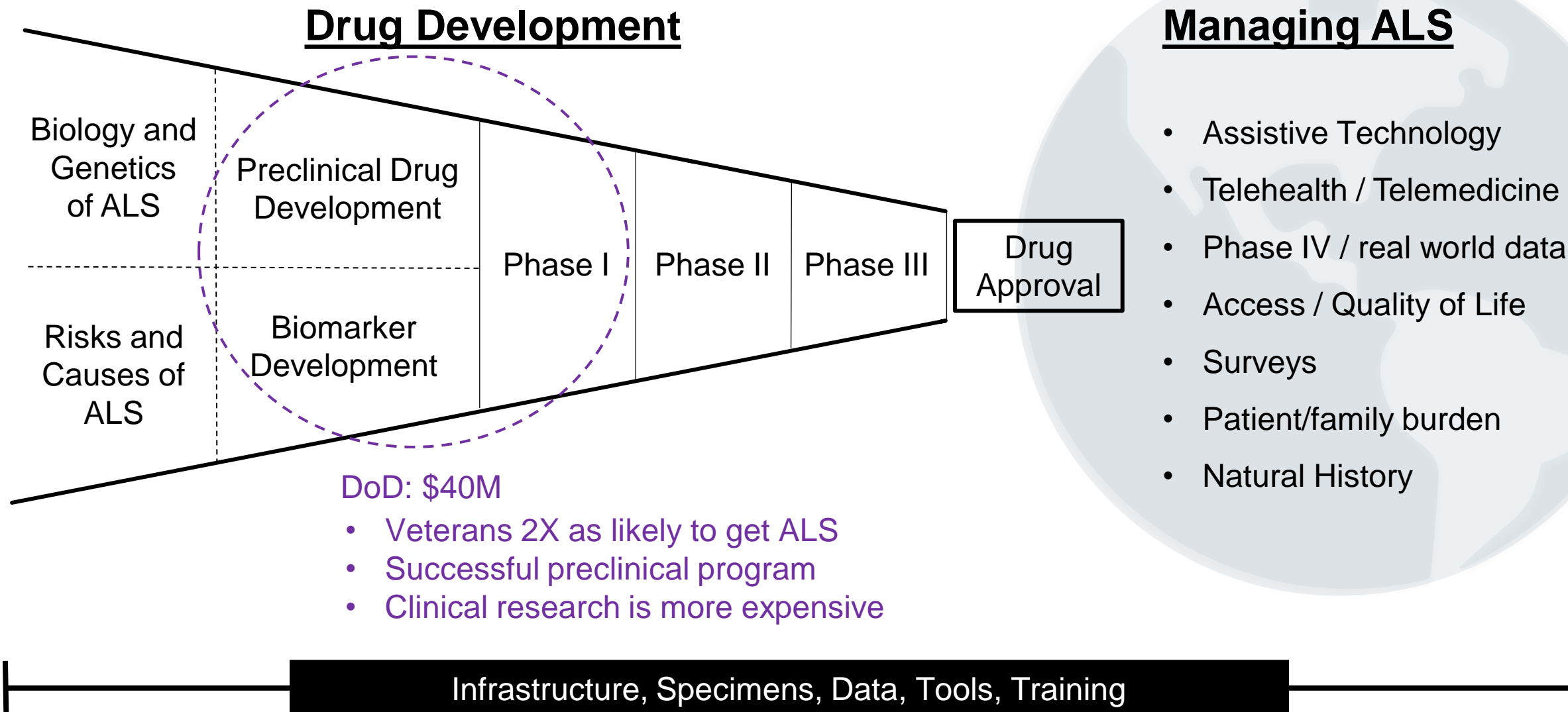


Managing ALS

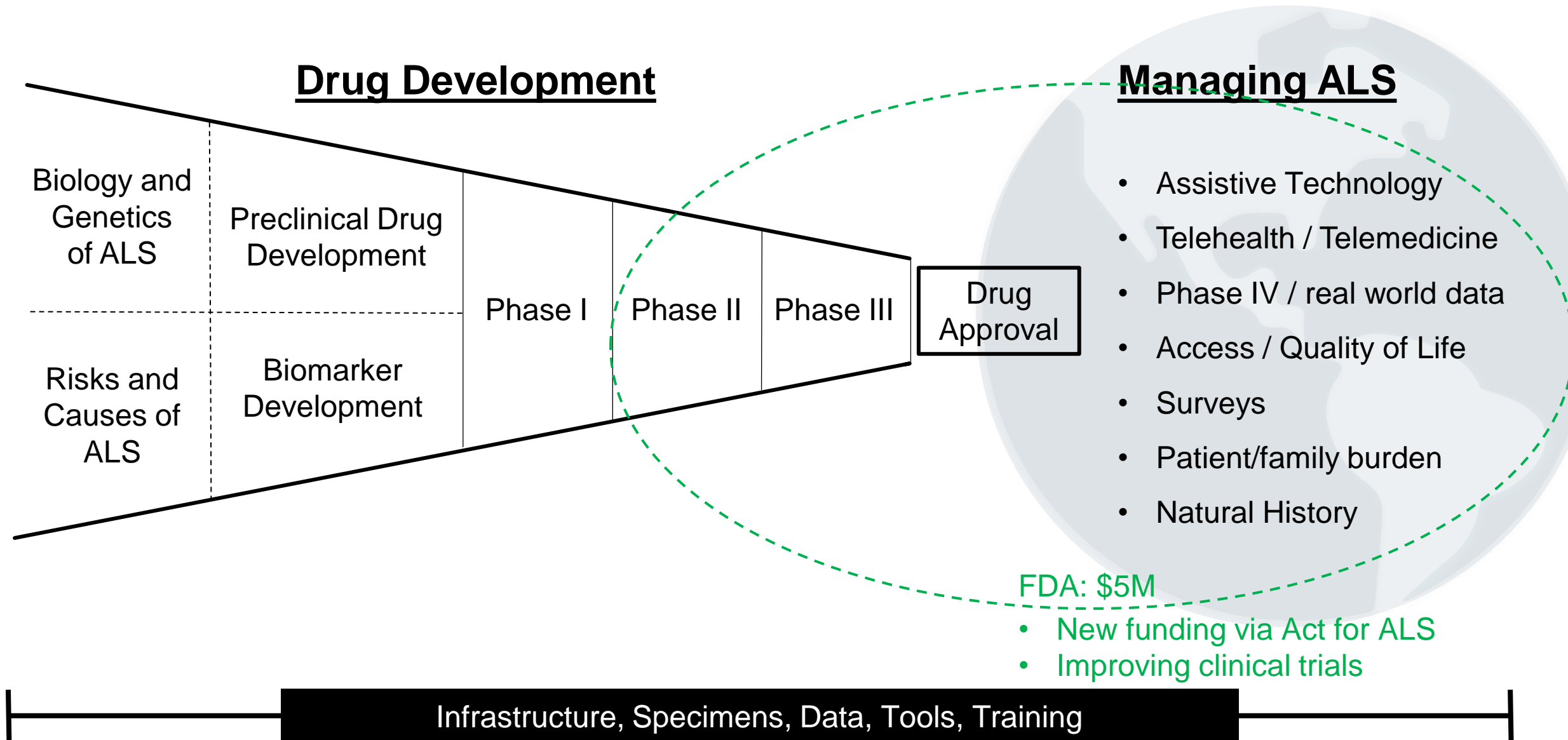
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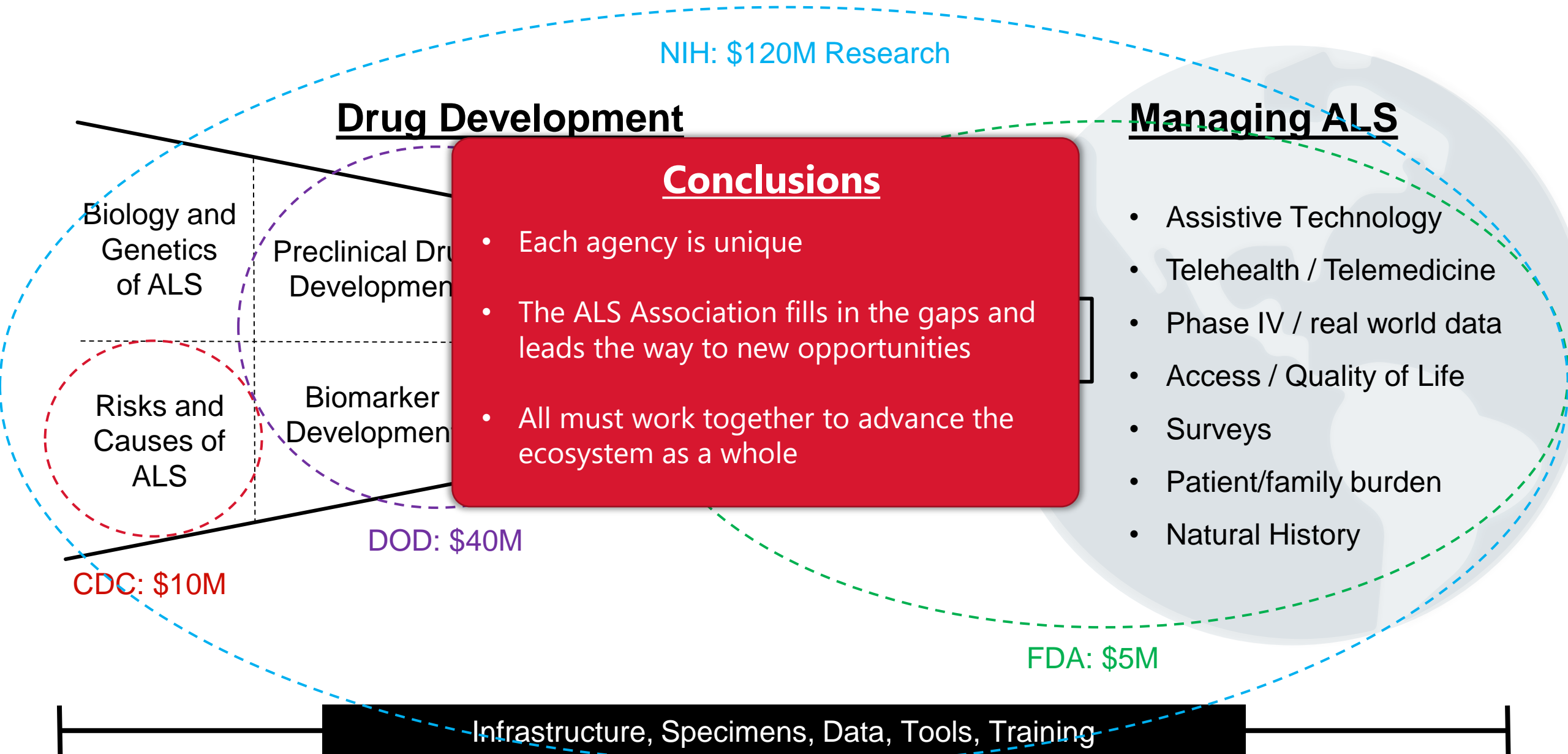
CURRENT CONGRESSIONAL FUNDING OF ALS RESEARCH - DoD



CURRENT CONGRESSIONAL FUNDING OF ALS RESEARCH - FDA



CURRENT CONGRESSIONAL FUNDING OF ALS RESEARCH



QUESTIONS & ANSWERS



ALS
ASSOCIATION

ADVOCATING FOR ALS RESEARCH

WINNING APPROPRIATIONS SUPPORT

DENISE BAILIN

Director, Congressional Affairs

ALS
ASSOCIATION



State of Play: Funding for ALS Research

- **Congress debating funding for government**
 - Requesting input from constituents
- **President released budget for government**
 - Congress has final say
- **We must tell Congress to increase ALS research funding**

State of Play: Dear Colleague Letter

- **What is a Dear Colleague Letter?**
 - “Congressional Petition”
- **ALS Research Dear Colleague Letter**
 - House letter – launched
 - Senate letter – launching soon

Impact Of ALS Research Dear Colleague Letter

- Increased funding for ALS research in our Dear Colleague Letter
- Members of Congress only sign on if they hear from constituents
- **More signatures = increased support for ALS funding**



ALS Research At The Department Of Defense

- **Current Funding: \$40 million**
- Only federal funding specifically for ALS research
- Research bridges ideas to preclinical innovation
- More clinical trials

MILITARY VETERANS ARE
2X
AS LIKELY TO DEVELOP ALS

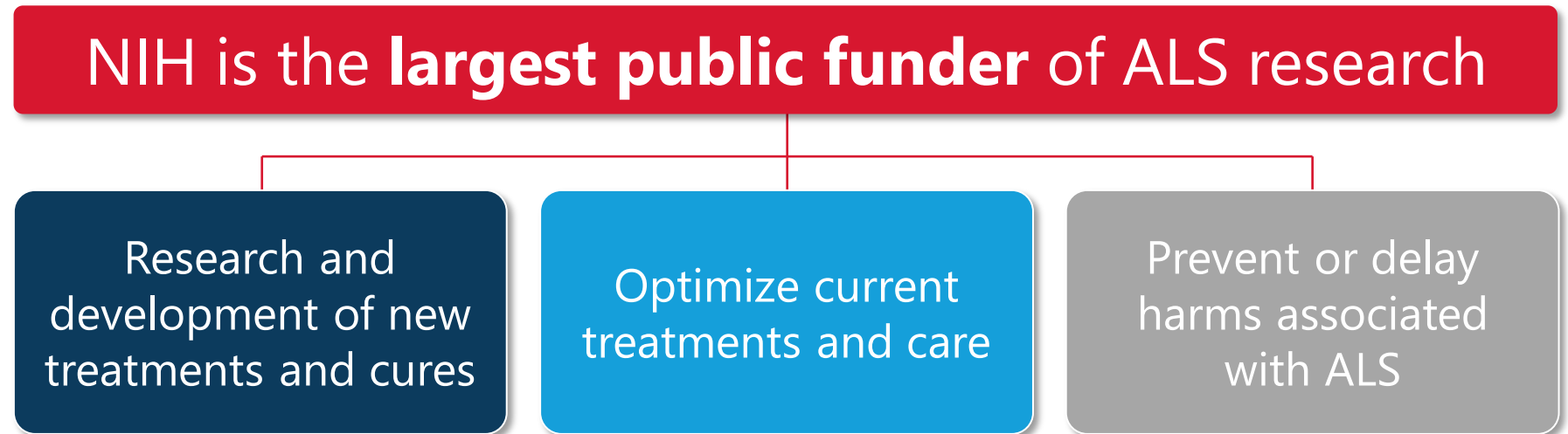
CURRENT FUNDING
CAN ONLY GRANT
25%
APPLICATIONS

OUR ASK

\$80 million for the Department of Defense ALS Research Program (ALSRP)

ALS Research at NIH

- **Current Funding: \$120 million**



OUR ASK

Provide \$150 million for research at the National Institutes of Health

ALS Registry and Biorepository at CDC

- **Current Funding: \$10 million**

Funds research
on causes, risks,
and prevention

Collects data
and bio-samples
for researchers

Connects
patients
to trials

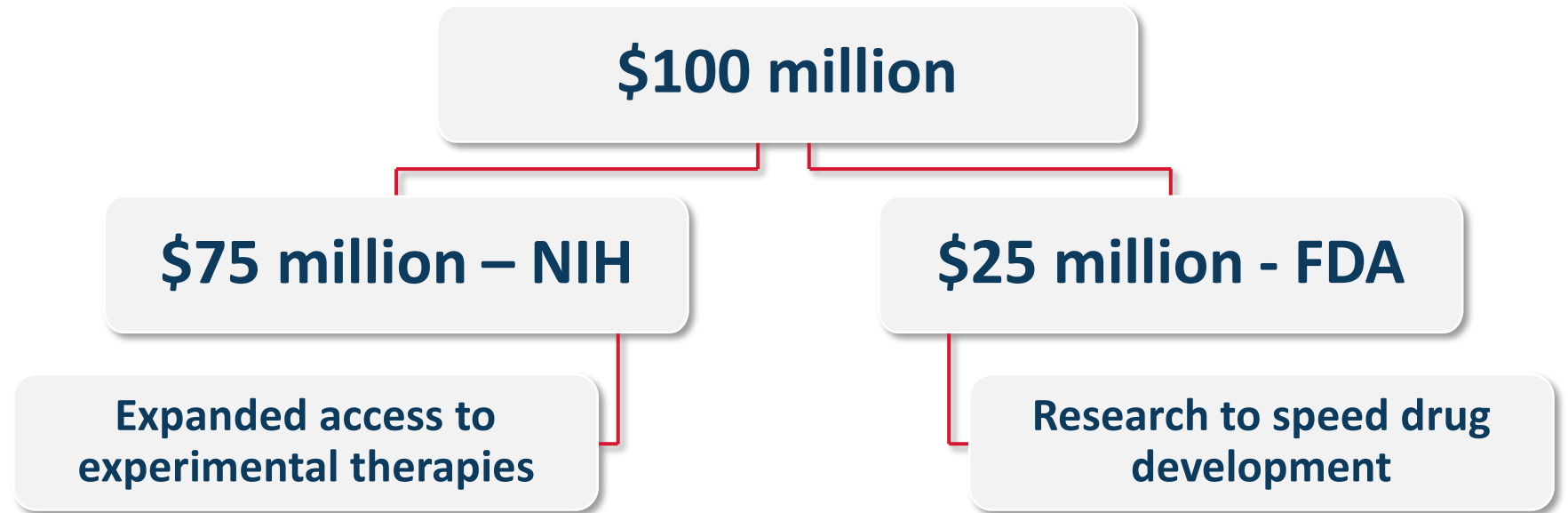
Measures
incidence and
prevalence

OUR ASK

- **\$15 million for the National ALS Registry and Biorepository**
- **An initiative to prevent ALS for veterans and active-duty soldiers**

ACT for ALS Act

- **Current Funding: \$80 million**



OUR ASK

Provide full funding for the ACT for ALS Act - \$100 million

RAISING AWARENESS

STEVE KOWALSKI

ALS Advocate



ALS
ASSOCIATION

TAKE ACTION

ALS ADVOCACY BEST PRACTICES

DUSTIN PERCHAL

Director, Advocacy Engagement & Mobilization
The ALS Association

DANIEL CRAMER

Associate Director, Congressional Affairs
The ALS Association



Be Persuasive in Three Steps



THE HEAD
State the Facts



THE HEART
Share Your Experience



THE HAND
Make the Ask

Online:

ALS.org/ActionAlert

Text:

855-469-2621 text "research"

Scan QR Code:

Point your camera on your phone or tablet at the QR code until a banner appears





TAKE ACTION!

ALS ASSOCIATION My Officials Federal State Log an Interaction Log a Relationship Share Your ALS Story **Sign Up**

Ask Congress: Sign the FY2024 ALS Research Appropriations Dear Colleague Letter

Congress makes critical decisions about the future of ALS research through the annual appropriations process. Our top advocacy priority each year aims to increase federal funding to support research and the search for treatments and cures for ALS. Federal funding for ALS research and programs at the National Institutes of Health (NIH), the Food and Drug Administration (FDA), the DOD ALS Research Program and the CDC National ALS Registry must be increased exponentially to provide new treatment options to cure and prevent ALS.

ALS champions Representatives Mike Gallagher (R-WI), Jason Crow (D-CO), Brian Fitzpatrick (R-PA), and Joe Courtney (D-CT) released the letter with the goal of enlisting their colleagues in our fight.

Join our campaign today by urging your member of Congress to add their name to the FY2024 ALS Appropriations Dear Colleague letter.

Act now!

[Sign up with Facebook](#)

Or Register Below

First Name	Last Name
<input type="text" value="First Name"/>	<input type="text" value="Last Name"/>
Email	Address
<input type="text" value="Email"/>	<input type="text" value="Street Address, City, and State"/>
Cell Phone Number	Thank you for joining our campaign. By providing your mobile phone number you consent to receive recurring text messages from our organization. Message & Data Rates May Apply. Text HELP for Info. Text STOP to opt out. No purchase necessary.
<input type="text" value="+1"/>	
What is your connection to ALS?	
<input type="text" value="Select..."/>	

Submit

Dear Colleague Letter Action Alert



Online: ALS.org/ActionAlert
Text: 855-469-2621 text "research"
Scan: QR Code with your phone or tablet



Personalize Your Message & Submit

Act now!

US Representative Don Beyer

Subject

Please Sign the FY2024 ALS Appropriations Dear Colleague Letter

Message

Dear Representative Beyer:

As your constituent and someone who is personally impacted by ALS, I am asking you to join the fight to end ALS by signing on to the fiscal year 2024 ALS Appropriations Dear Colleague letter.

With your support, we can drastically accelerate the fight against ALS.

This letter requests new and increased investments in ALS research, specifically:

1. Fully fund the ACT for ALS Act at \$100 million including:

\$25 million in funding for FDA's Rare Neurodegenerative Disease Grant Program

Sincerely,

Dustin Perchal

1300 Wilson Blvd, Arlington, VA 22209, USA

Submit



Online: [ALS.org/ActionAlert](https://www.als.org/ActionAlert)
Text: 855-469-2621 text "research"
Scan: QR Code with your phone or tablet



Follow It Up With A Tweet



My Officials Federal - State - Log an Interaction Log a Relationship Share Your ALS Story Hello, Dustin! -

Follow It Up With A Tweet: Increase Funding for ALS Research

Dustin:

Thank you for asking your member of Congress to support the FY2024 ALS Appropriations Dear Colleague letter. Your message has been sent.

If you have a Twitter account, please click the blue button next to the tweet to urge your member of Congress to support expanded funding for ALS research.

Act now!

US Representative Don Beyer

As your constituent & someone impacted by #ALS, I urge @repdonbeyer to support #ALSResearch. Add your name to the FY2024 ALS Appropriations Dear Colleague letter today: [#FundALSResearch](https://als.org/Dear-Colleague)

Send


All Finished!



Online: **ALS.org/ActionAlert**
Text: **855-469-2621** text "research"
Scan: **QR Code** with your phone or tablet











Post Your Tweet

×
 Everyone ▾

As your constituent & someone impacted by [#ALS](#), I urge [@reardonbeyer](#) to support [#ALSResearch](#). Add your name to the FY2024 ALS Appropriations Dear Colleague letter today: als.org/Dear-Colleague [#FundALSResearch](#)

🔔 Everyone can reply

       |  Tweet



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Thank You for Taking Action!

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Dustin,


Thank you for taking action in support people living with ALS and the entire ALS community. We are grateful for your support.


Please follow @alsassociation on Twitter for the latest updates on this issue and more!


The ALS Association

 You've earned 2 points!

 Share on Facebook

 Share on Twitter

 Share on LinkedIn

 Share on Pinterest

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#ALSAdvocacy



QUESTIONS & ANSWERS



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FINAL REMINDERS

MELANIE LENDNAL

Senior Vice President, Public Policy & Advocacy



ALS
ASSOCIATION

ALS ASSOCIATION ADVOCACY UPDATE

THANK YOU

FOR ATTENDING OUR WEBINAR



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