
The Role of Non-Profit Organizations in Disease Specific Research and Innovation

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American Diabetes Association

American Diabetes Association

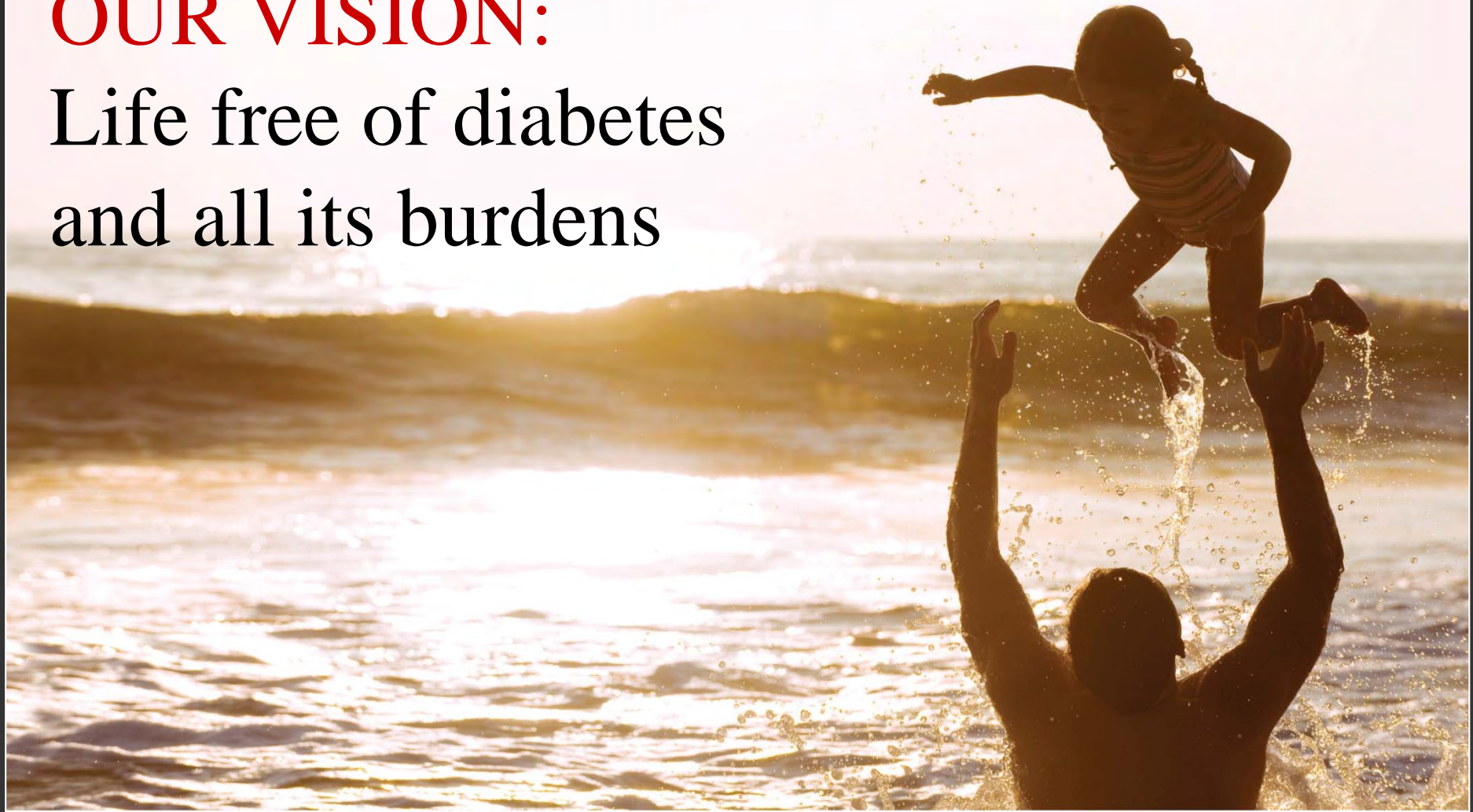
- Voluntary Health Association
- Founded in 1940
- Non-governmental, non-profit organization
- ~\$200M/year budget-funded primarily through public donations
- Governed by volunteer Board of Directors & National Committees
- Staff of ~800 full time employees, National home office in DC and ~80 local offices throughout the US
- Professional membership of ~14,000
- Mission- ***“To prevent and cure diabetes, and improve the lives of all people affected by diabetes”***



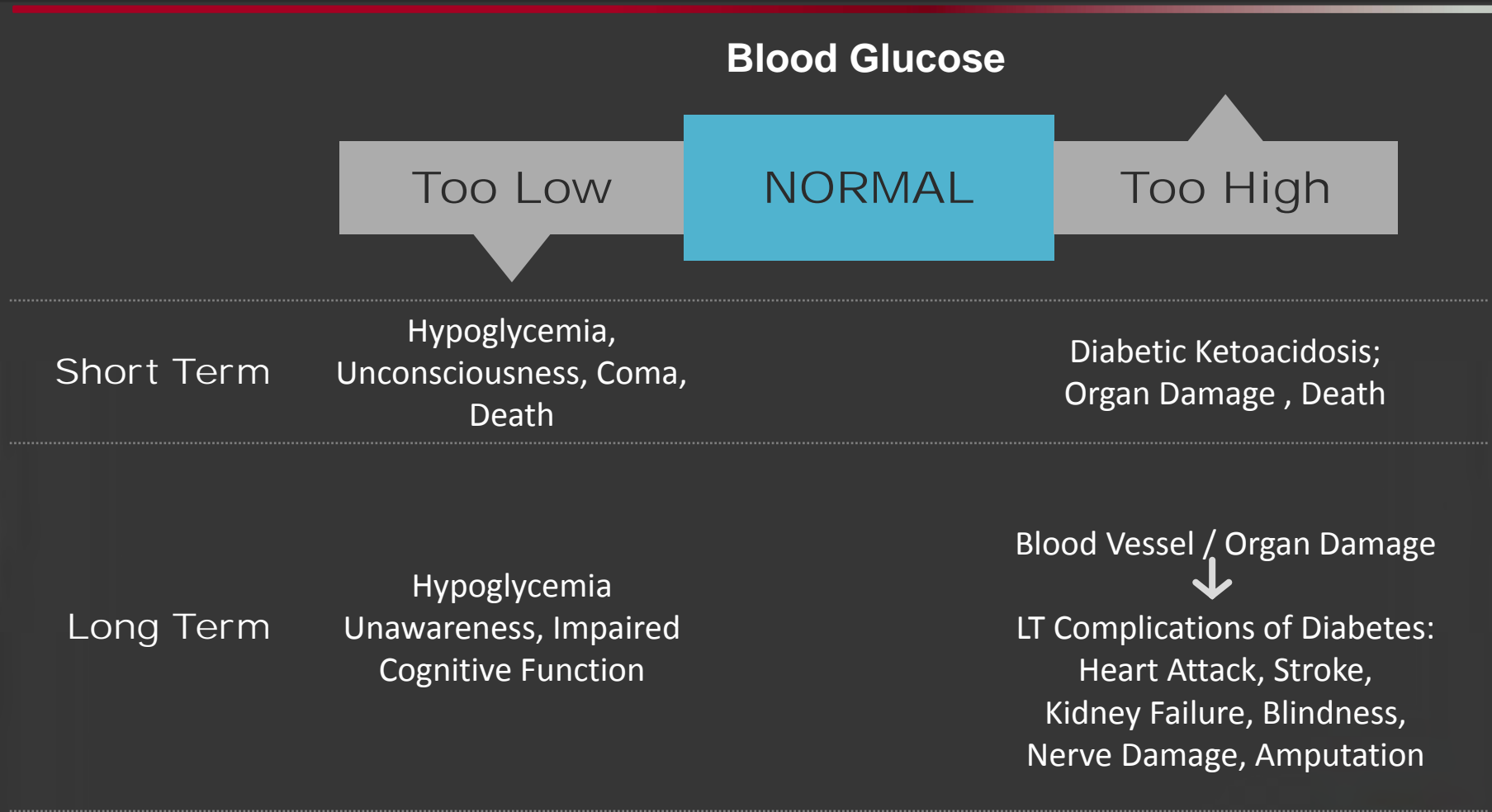
 American Diabetes Association.

OUR VISION:

Life free of diabetes
and all its burdens

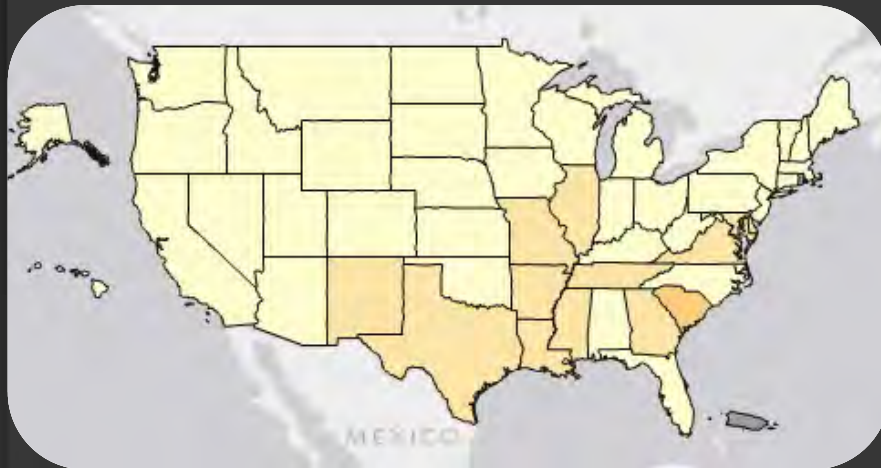


Diabetes and its Complications

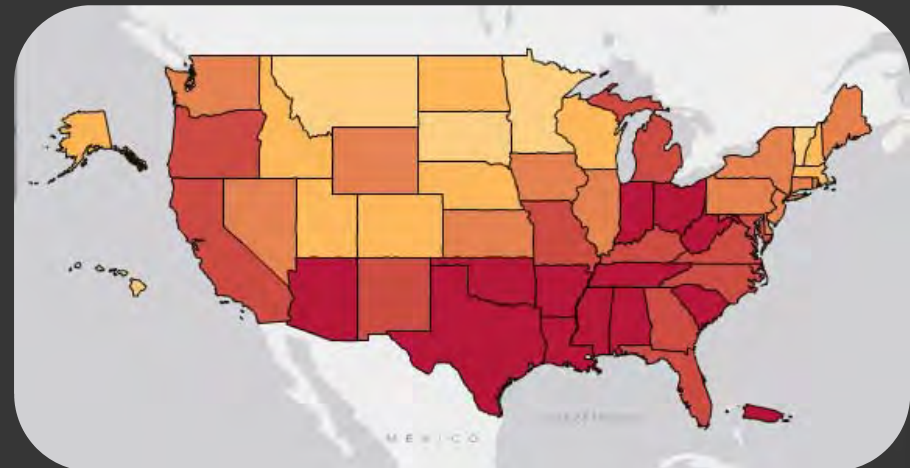


The Rising Tide of Diabetes in the US

1994



2012

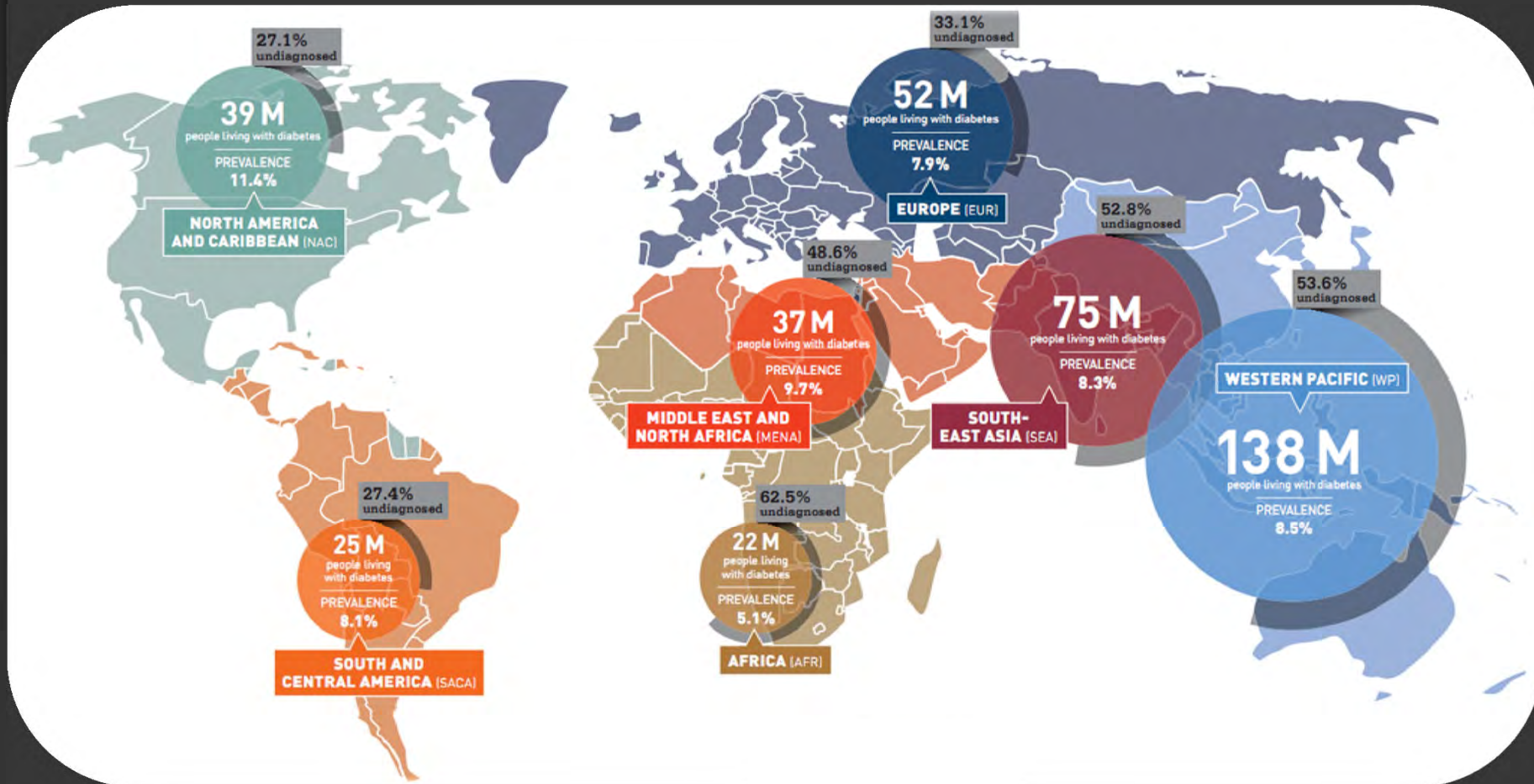


■ 0%-4.9% ■ 5%-5.9% ■ 6%-6.9% ■ 7%-7.9% ■ 8%-8.9% ■ 9% -9.9% ■ 10% +

Diabetes prevalence

Annual Cost of Diabetes in the US is \$245B USD

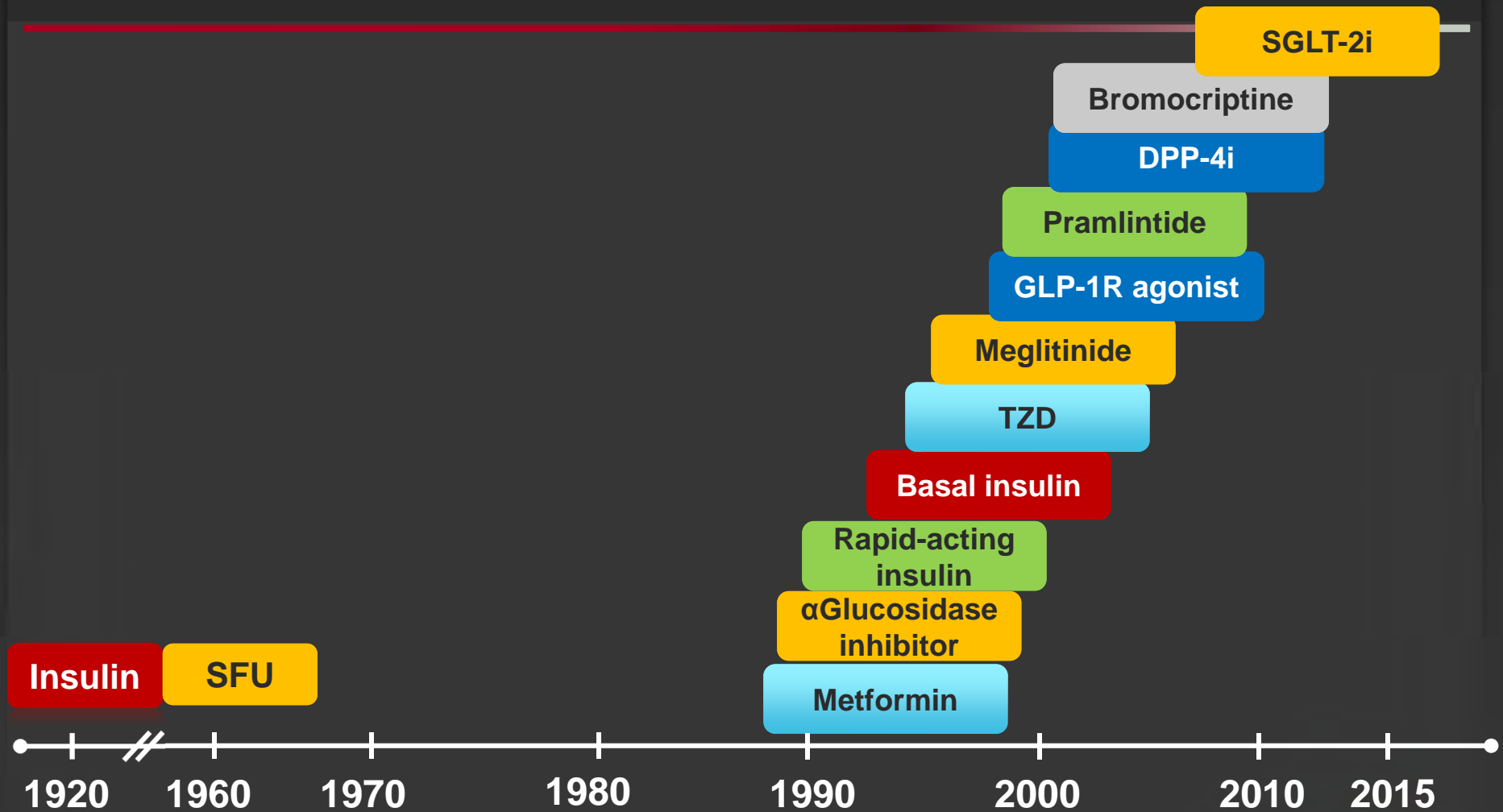
Diabetes has a Significant Global Impact



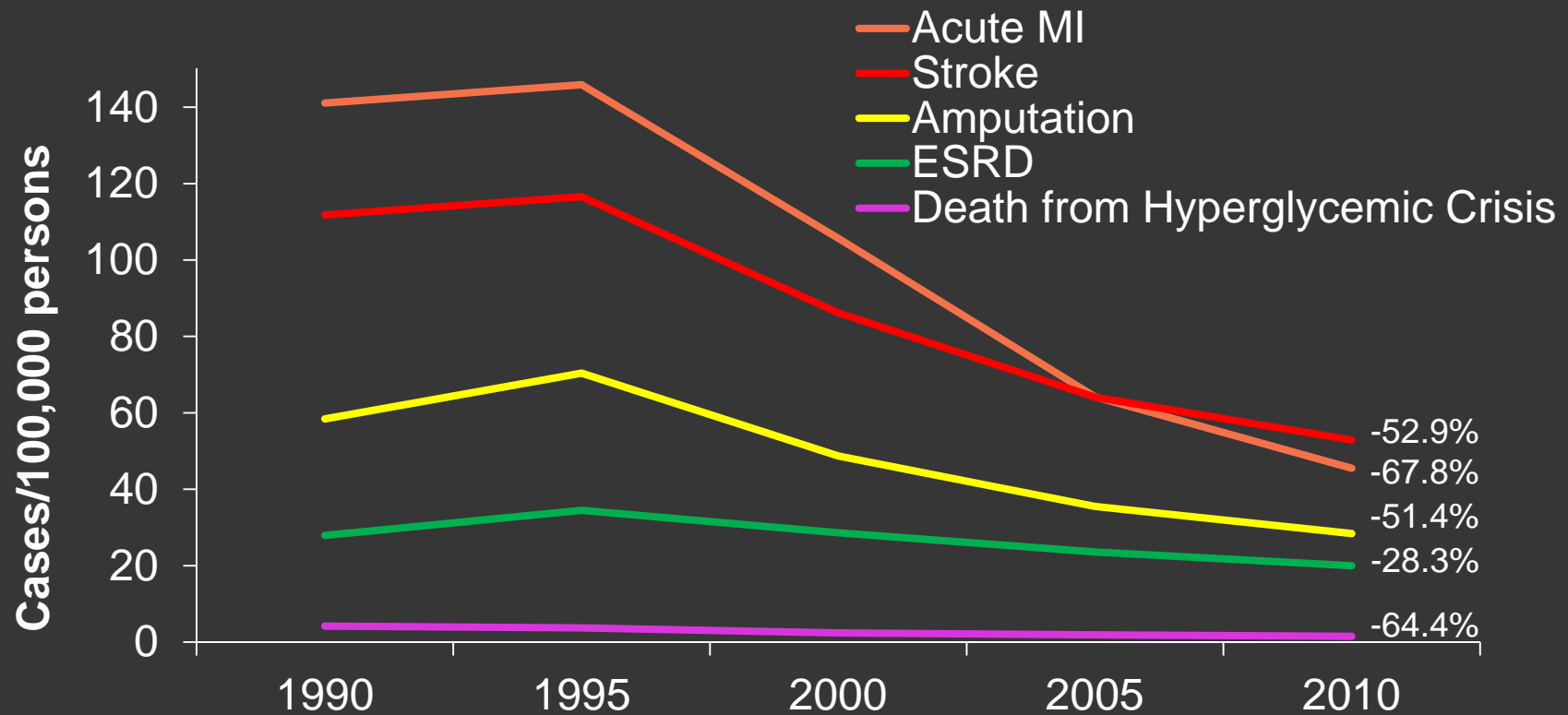
Annual Global Cost of Diabetes is \$548B USD

IDF Diabetes Atlas, 6th Edition update, 2014, accessed May 22, 2015

Therapeutic Advances for Diabetes



Dramatic Reductions in Complication Rates



Research is Central to the ADA Mission

Professional Resources

Scientific sessions
Professional education
Peer-reviewed journals
DiabetesPro

Medical Information

Clinical practice recommendations
(Guidelines)
Medical publications

RESEARCH

Direct research funding
Collaborative initiatives

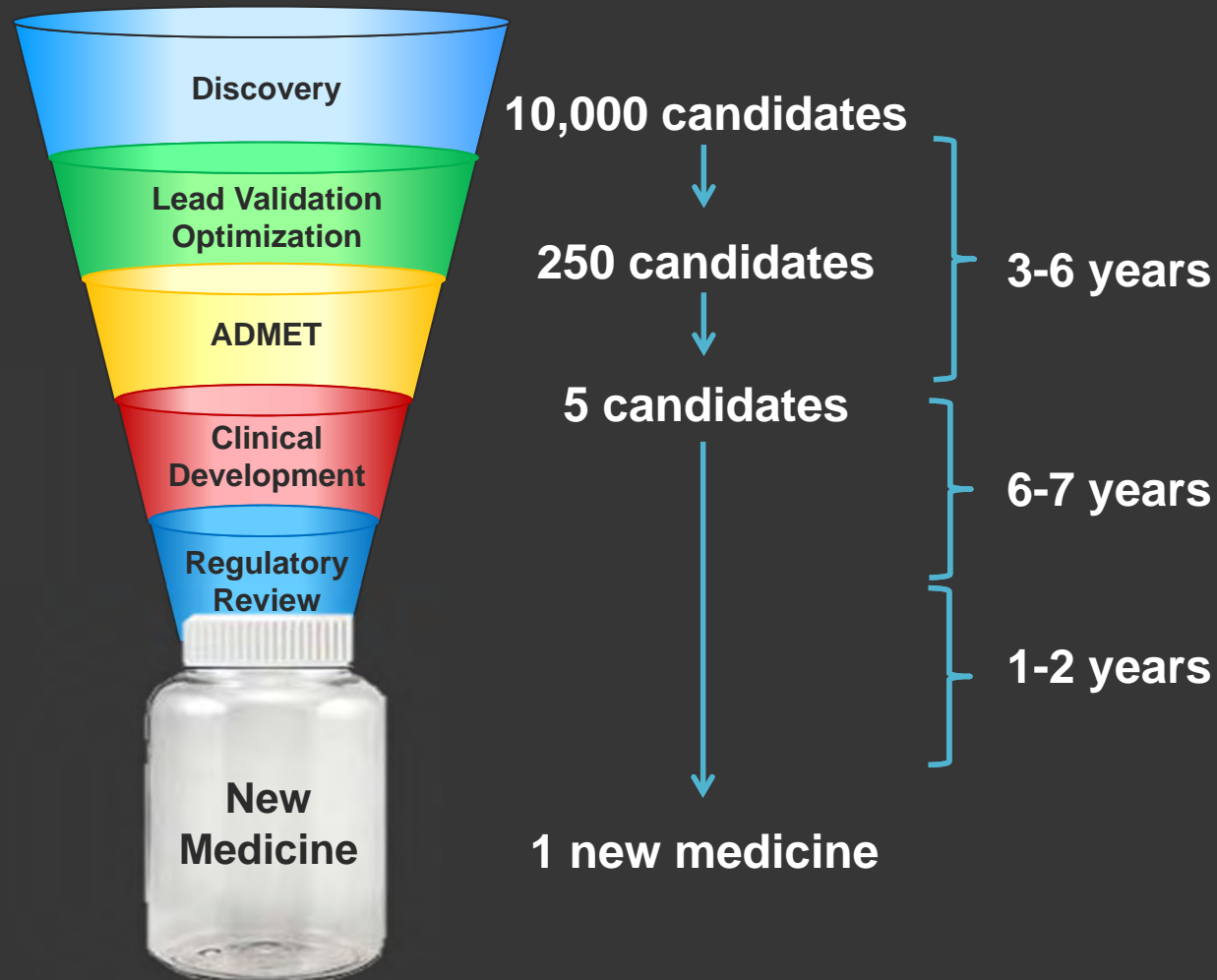
Advocacy

Research support
Diabetes prevention and care
Legal advocacy and support
Legislative action

Communities

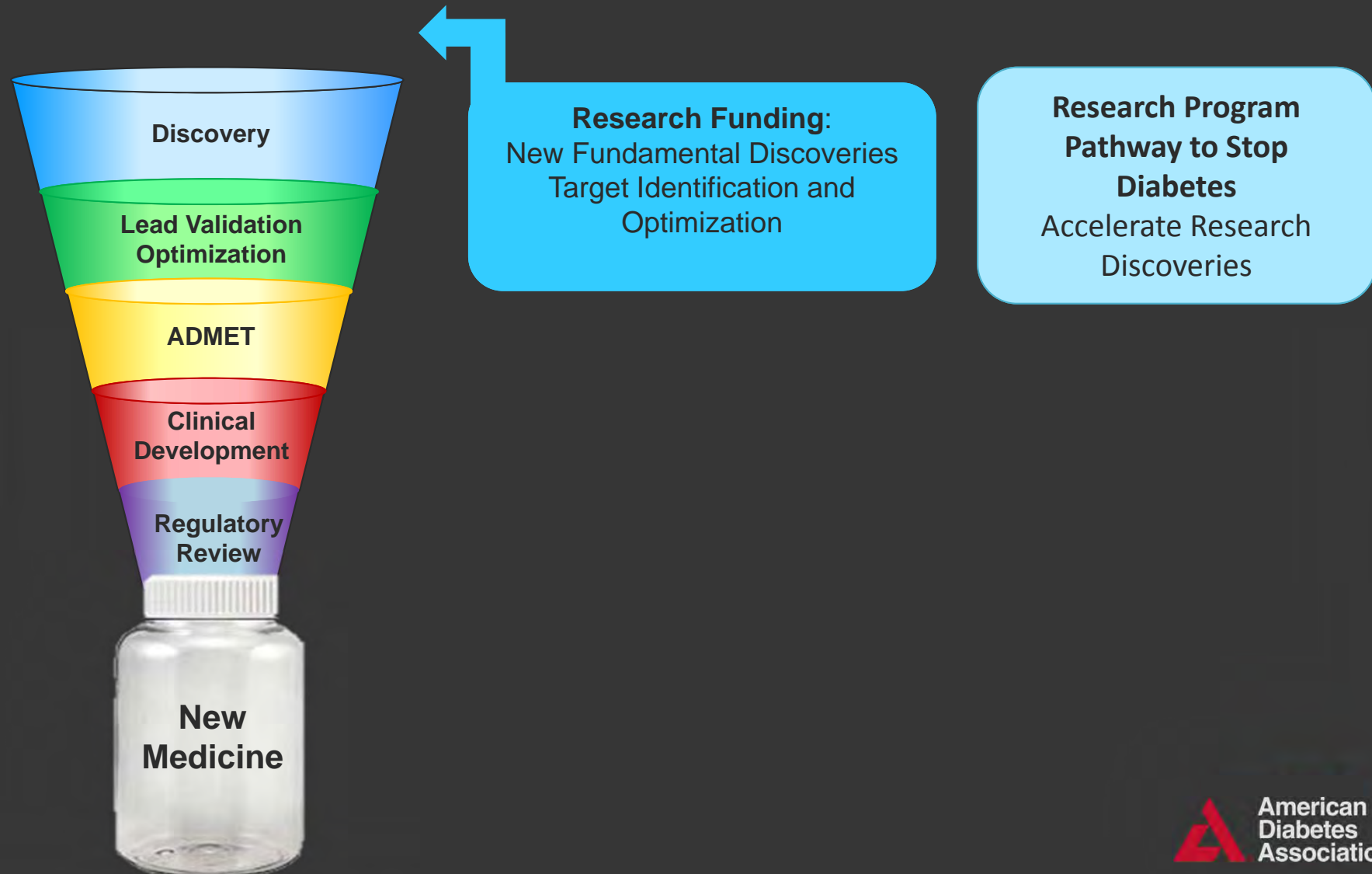
Community health education programs
Center for information and community
support
Forecast magazine
Diabetes.org

Pathway to Improved Treatments and Cures



Drug Development is a HIGH RISK proposition

Accelerating Progress for People with Diabetes



American Diabetes Association Research Programs

Research advances are essential to help people living with diabetes today, and are the only way to ultimately cure diabetes

Since Program inception in 1952:

- » Nearly **4,500** research projects have been funded
- » More than **\$700** million has been invested in diabetes research

In 2014 alone, the Research Program:

- » Made **\$30** million available for research
- » Included more than **375** active research projects
- » Supported investigators and institutions in the United States, Canada and EU

Research Program Objectives

- » Support high-quality academic science across the spectrum of diabetes research
- » Encourage new investigators to dedicate their careers to diabetes research
- » Support innovative research with the potential to have a significant impact for people with diabetes

Research Funding Process

Researchers submit their original proposals

- We receive ~1000 applications/year for research in all areas relevant to diabetes

Volunteer experts on the Research Grant Review Committee review proposals

- Three diabetes experts review each grant-and then discuss their reviews in a live meeting
- provide priority scores and written feedback to applicants
- Compiled scores are averaged to get final priority score

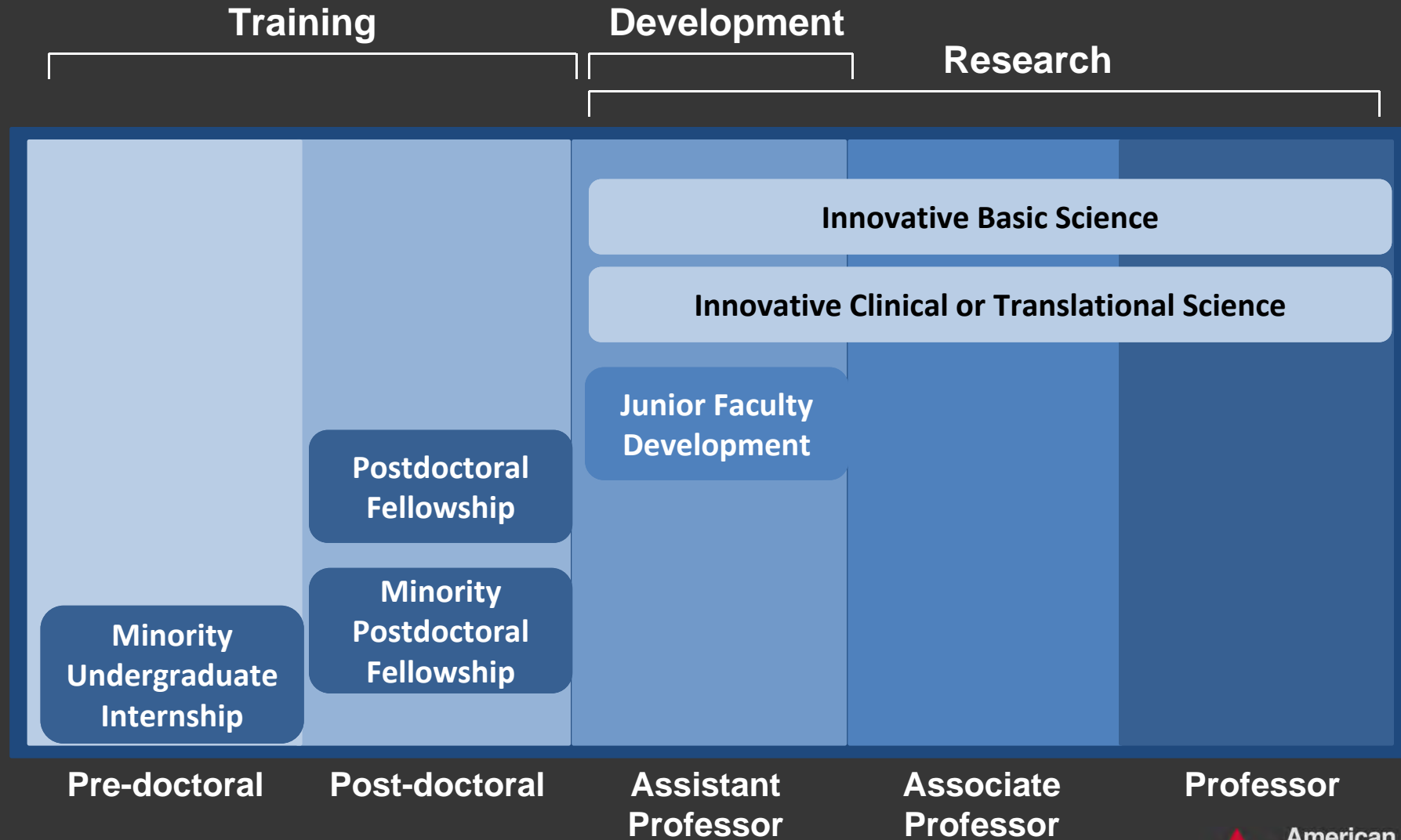
Volunteer Research Policy Committee reviews rankings and recommends funding

- We support ~10% of the grants we receive each year

Supported projects are monitored for the life of the grant

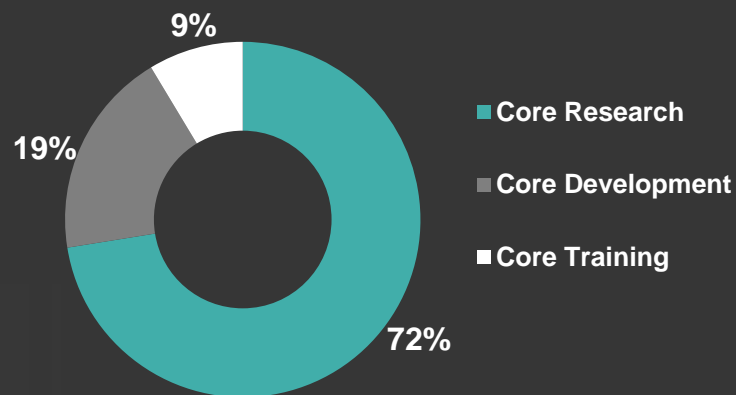
- Scientific data, publications, patents, career progression, subsequent funding

Association Research Grant Opportunities

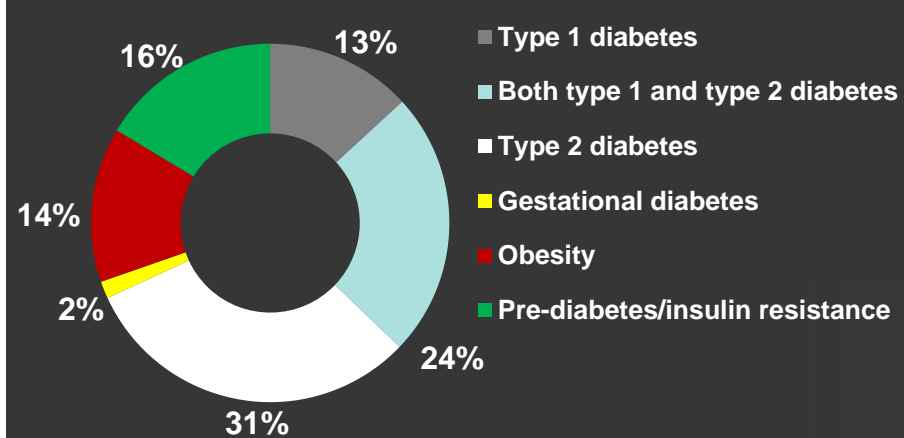


Grant Portfolio Distribution

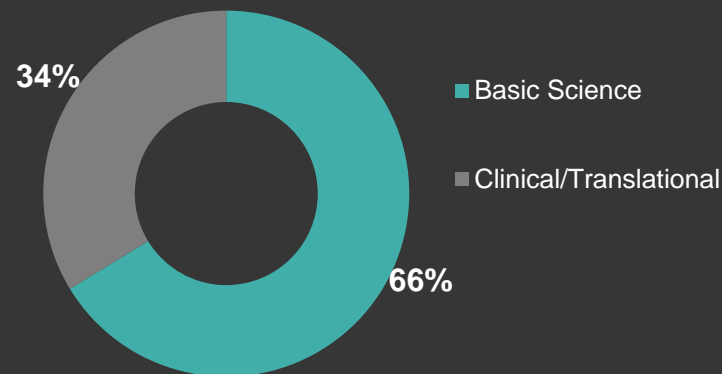
Funding by Award Type (Percent of Dollars Distributed in 2014)



Funding by Diabetes Type (Percent of Dollars Distributed in 2014)



Funding by Research Type (Percent Dollars Distributed in 2014)



Research Programs Accomplish Key Goals

98% remain in diabetes research

6 publications per award

82% of early career recipients receive promotions

85% receive subsequent federal funding

\$421 million
subsequent research funding

\$244M
Federal
Funding

\$113M
Collaborative
Funding

\$63M
Non-Profit
Funding

\$56 million
initial ADA funding



PATHWAY TO STOP DIABETES

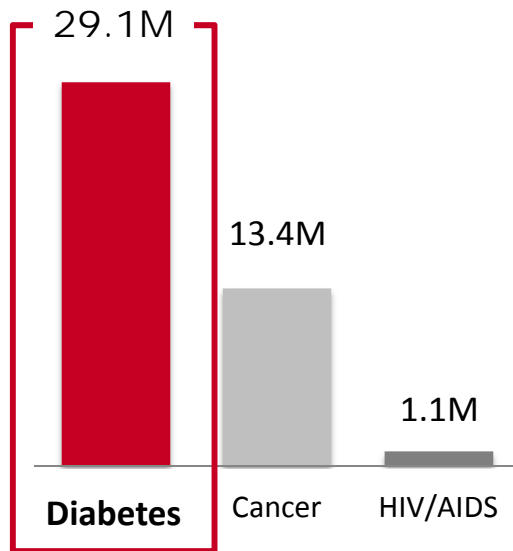
A RADICAL NEW ROAD **FOR RESEARCH**

 American Diabetes Association®

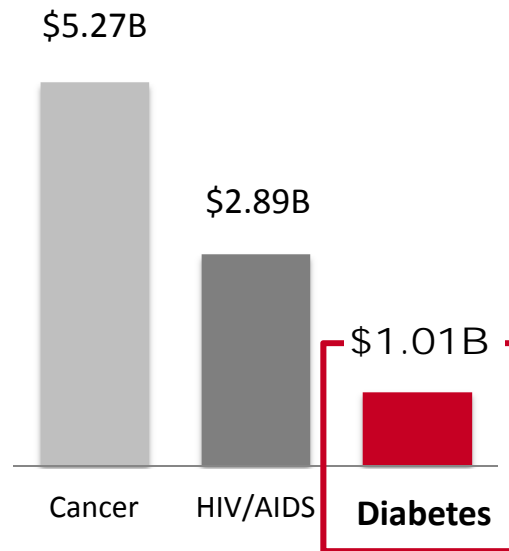
ResearchFoundationSM
Science. Progress. Hope.

Diabetes Research: Vastly Underfunded vs. Its Impact

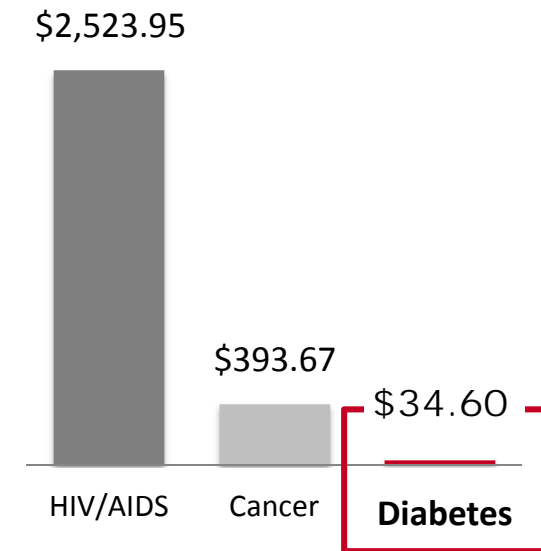
Prevalence in United States⁹



NIH Funding¹⁰



NIH Funding per Affected Person



Yet, More People Die Today from Diabetes than Breast Cancer and AIDS Combined

A Generation of Potential Is Lost



Young,
Talented
Researchers

Substantial
Education Debt



Grant Review System that
Rewards Established
Researchers in Current Field



Paucity of Funding for
Diabetes Research



Abandon Less Well Paid
Research Careers



Hard to Establish or Change
Research Focus



Low Dollars, Low Profile

The Average Age for First NIH Project Grant Is
42 Years Old!



PATHWAY TO STOP DIABETES

1

Attract Brilliant
Minds at the Peak of
Their Creativity

2

Invest in
People,
Not Projects

3

Provide Freedom,
Autonomy and
Resources

Pathway to Stop Diabetes

What Differentiates Pathway from Other Programs?

- Funding ... **Awards of Up to \$1.625 Million**
- Security ... **5 to 7 Years of Support**
- Autonomy ... **The Freedom to Innovate, to Explore, to Blaze New Trails**
- Mentoring ... **Guidance from Distinguished Scientists, Business Leaders and Other Major Donors**
- Collaboration ... **Opportunities to Advance Research and Careers Through Symposia, Speaking Opportunities and Technology**

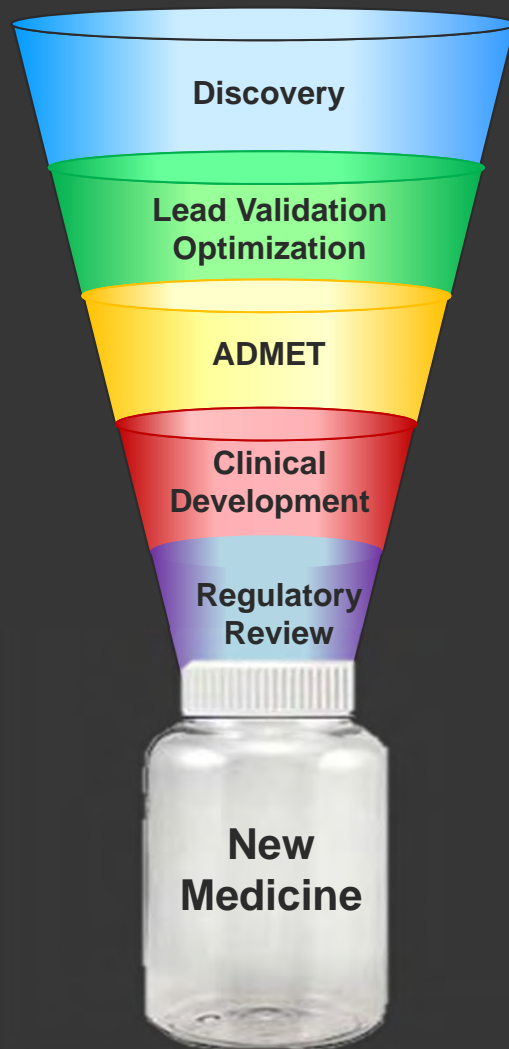
Mentorship and Guidance



Pathway Symposium

- Pathway Scientists meet in person each year
- Mentor Advisory Group, Association Leadership, Donors, and Sponsors
- Encourages mentoring and development of collaborations
- High level of engagement and quality scientific exchange, lasting relationships

Accelerating Progress for People with Diabetes



Scientific and Medical Journals

diabetes Diabetes Care



Clinical Diabetes Spectrum



Scientific Sessions

Annual Scientific Meeting

- » Largest diabetes scientific congress
- » ~18,000 participants; 40% US / 60% International
- » Academic Researchers, Clinicians, Health Care Providers and Industry

Program

- » 865 Speakers in 94 Sessions
- » 50 Oral Abstract Sessions; 2,331 Poster Presentations
- » 60 Guided Audio Poster Tours
- » 10 Special Lectures and addresses
- » 17 Meet-the-Expert Sessions
- » 10 Interest Group Discussions



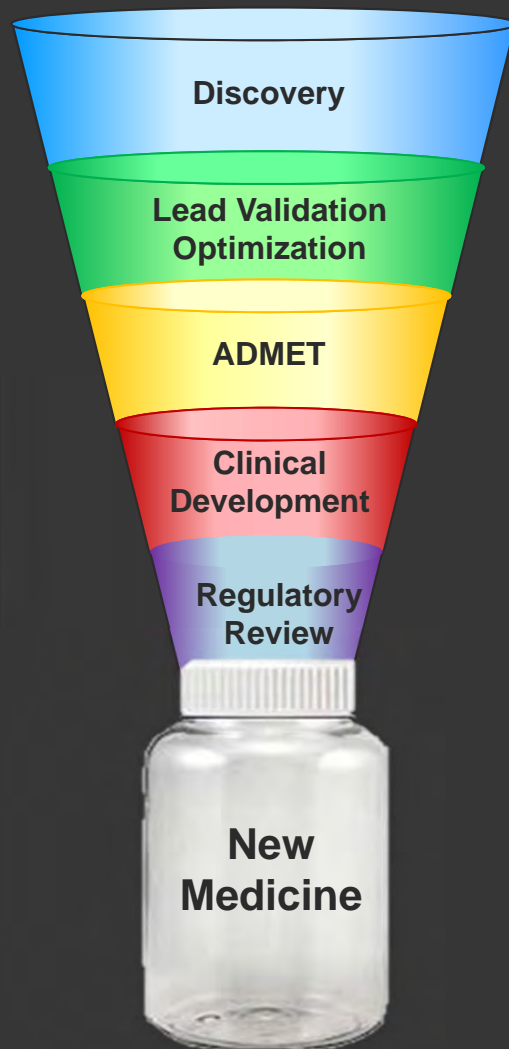


“Discovery” of Exendin-4

- **Glp-1 well characterized human peptide with insulinotropic activity, but short half-life**
- **John Eng, MD, discovered stable homologue, Exendin-4 in 1992 at Bronx VA in Gila monster saliva**
- **Patented, published and “marketed” to industry without success**
- **Presented at Scientific Sessions in June 1996**
- **Licensed in October 1996**
- **Approved as first in class GLP-1r agonist BYETTA in 2005**



Accelerating Progress for People with Diabetes



Advocacy:
Define Regulatory Pathways
Communicate Unmet Needs

Regulatory Process
Collaborate with Industry,
Researchers and FDA

Patient Advocacy in the Regulatory Process

Regulatory Pathways and Guidelines

- » Convene scientific panels to discuss and develop recommendations to address regulatory hurdles that impact people with diabetes
- » Input on proposed policies and guidelines



Patient Advocacy

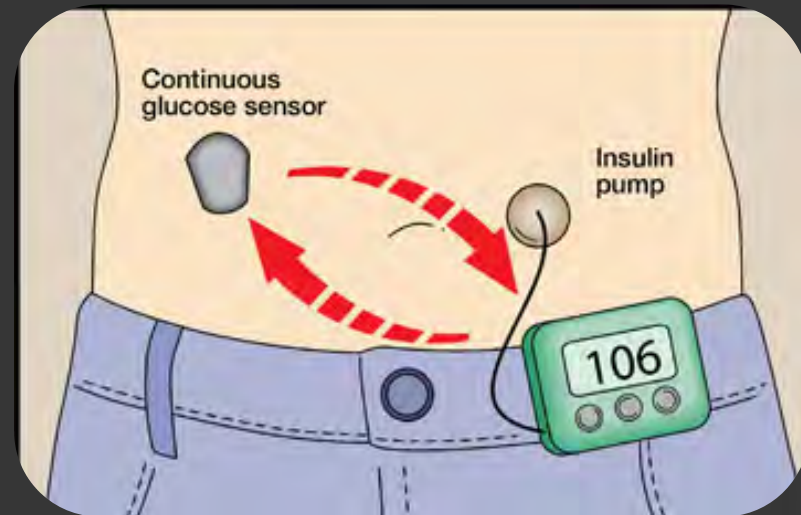
- » Expert staff or professional member representatives attend all FDA advisory panels
- » Provide public comment regarding the unmet needs and patient perspective



Regulatory Pathway for an Artificial Pancreas

Artificial Pancreas

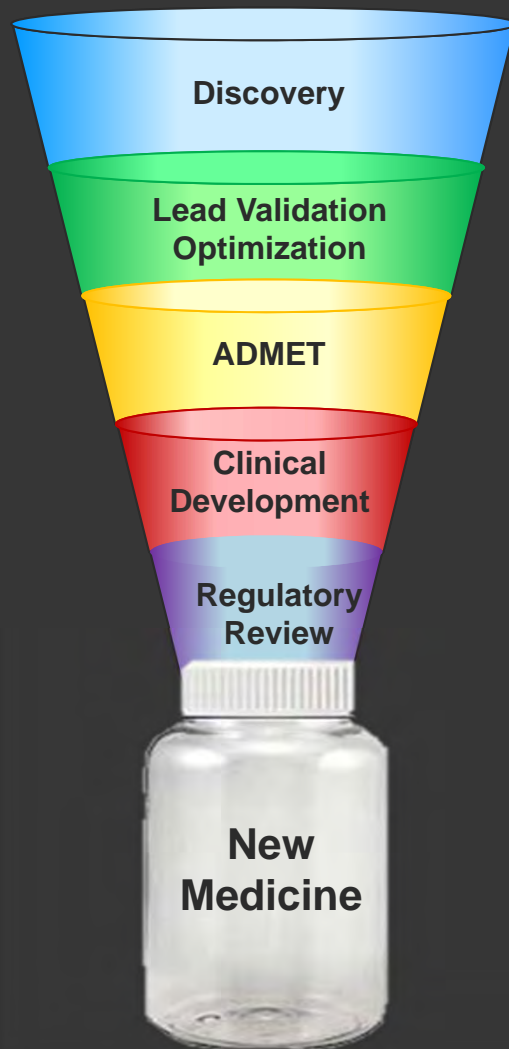
- » Complex, multi-component device
- » Utilizes therapeutics, devices and control algorithms
- » Significant safety considerations
- » No defined regulatory pathway



Advocacy effort – led by JDRF

- » 2010 assembled expert clinical panel to propose regulatory pathway
- » Worked with FDA to refine proposed guidance
- » Petitioned congress to advance development of AP
- » 2012 final FDA guidance approved
- » 2014 NIH issued RFA for \$20M to advance clinical studies of AP

Acceleration Progress for People with Diabetes



Medical Information and Clinical Care:
Standards of Care
Treatment Algorithms
Professional Education
Public Policy

Standards of Care
Educate Clinicians With
Latest Evidence-Based
Treatment Guidelines

Standards of Care Drive Clinical Practice

Diabetes Care[®]

THE JOURNAL OF CLINICAL AND APPLIED RESEARCH AND EDUCATION

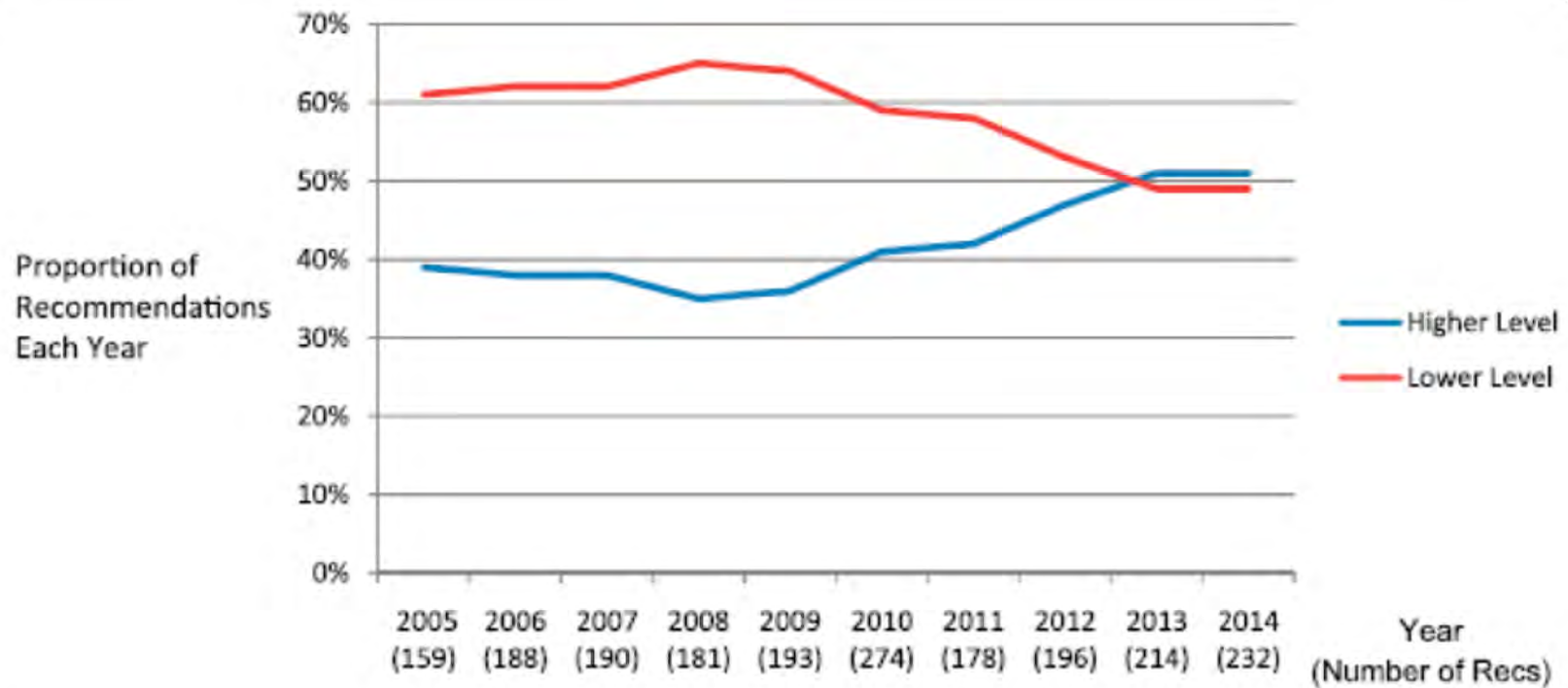
January 2015 Volume 38, Supplement 1

Standards of Medical Care in Diabetes—2015

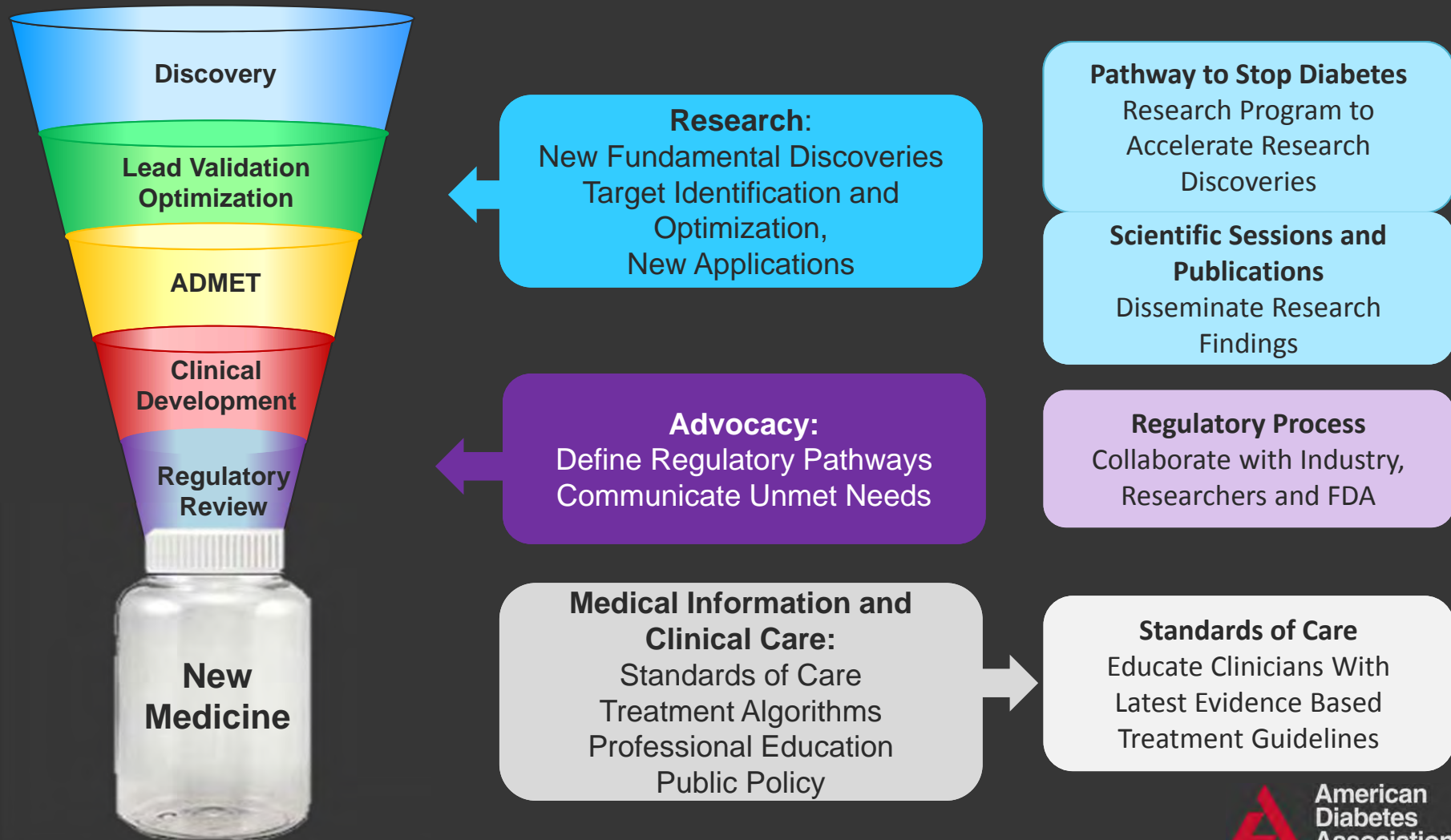
Translating research outcomes into clinical practice

- » Makes Evidence-based recommendations for all aspects of diabetes care
- » Updated and published each January
- » Informs medical practice in US and internationally
- » Informs public healthcare policies

Evidence Base for Clinical Recommendations



Acceleration Progress for People with Diabetes



Become Involved in Association Activities

Apply for Grants

- » Individual or training/development grants

Share your Data

- » Attend and present at Scientific Sessions and Research Conferences
- » Publish in Association Journals

Share your Expertise

- » Grant and Manuscript Review
- » Scientific Sessions or Conference Planning
- » National Committees

How to Get Involved

*Everything the Association does depends on volunteers-
we need scientific and medical expertise to accomplish our
mission*

Research Programs

- » Research Policy and Grant Review Committees

Scientific Meetings

- » Scientific Program Committees, Planning Committees and Interest Groups

Publications

- » Manuscript Reviewers and Editorial Boards

Advocacy

- » Ad-hoc workgroups, local and national advocacy

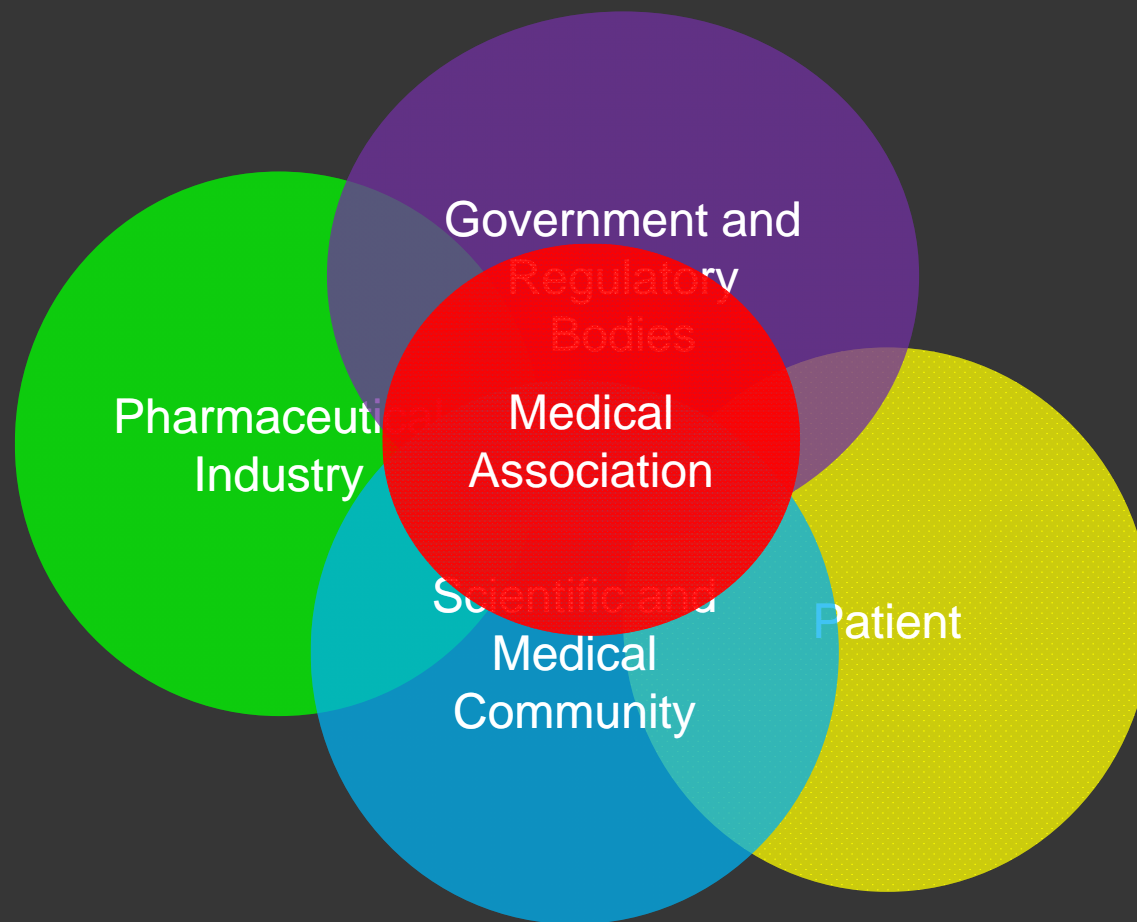
Standards of Care

- » Professional Practice Committee and professional education

Working with an Association Benefits Everyone

- **Support for you work**
- **Career development opportunities**
- **Network within your scientific community**
- **Influence Association activities and programs**
- **Participate in development of public policy**

Healthcare Ecosystem



Medical Associations are uniquely positioned as independent, patient-focused arbiters to integrate the components of a complex healthcare ecosystem to advance progress and innovation

Thank you!