



FOUNDATION  
FIGHTING  
BLINDNESS

Driving Research

**SAVING SIGHT**

ANNUAL REPORT 2017

# Table of Contents

Chairman’s Message ..... 1

CEO Report ..... 2

2017 Foundation Research Funding Commitments and Investment Highlights..... 3 - 4

Treasurer’s Report ..... 6 - 8

Board of Directors ..... 9

Scientific Advisory Board ..... 10 - 12

National Trustees ..... 13 - 14

Senior Staff ..... 15

National Chapters..... 16

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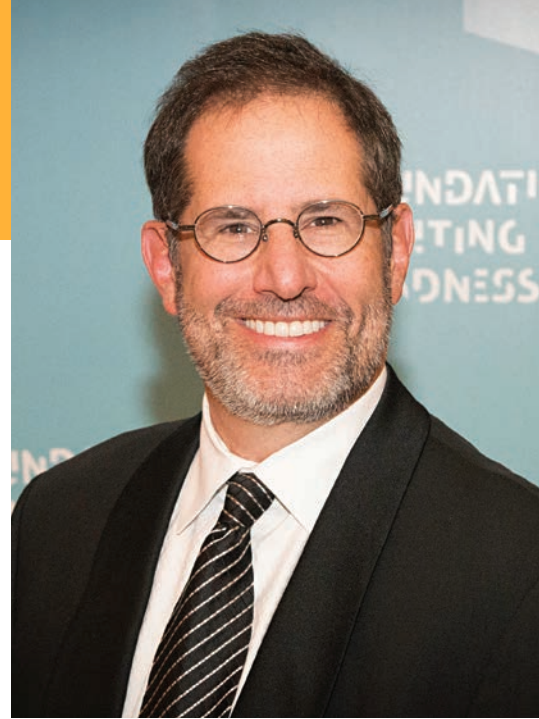
## Legacy Planning

Please consider, as part of your lasting legacy, remembering the Foundation Fighting Blindness in your will, trust, or other estate planning. For more information, visit our planned giving website at [www.myplantofightblindness.org](http://www.myplantofightblindness.org).

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# Chairman's Message



## David Brint, *Chairman*

I'm pleased to welcome you to the 2017 Foundation Fighting Blindness Annual Report. While I have the privilege of opening this report, it takes a team effort to achieve FFB's mission. I encourage you, our most loyal donors, to take a few minutes to read the full report. In doing so you will see how your generosity has helped fuel a revolution in inherited retinal disease science – one that puts us solidly into an era of clinical trials and on the cusp of providing treatments for some retinal degenerations!

FFB provides the all-important seed money to support the work of the world's best retinal disease scientists. We propel their best ideas forward so they can be studied, attract larger funding investments from private and public sources, and, in a few cases, earn FDA approval!

This strategy has yielded strong dividends. One of the most significant was this past October's recommendation by the U.S. Food and Drug Administration Advisory Committee on Cellular, Tissue, and Gene Therapies that Spark Therapeutics' gene therapy for the treatment of RPE65 gene mutations be approved. This anticipated therapy will not only be life-changing for people with LCA caused by the RPE65 mutation, it will help move additional gene-based ocular and other treatments forward. See pages 3–5 for other highlights of the year and for a list of ongoing clinical trials that have their roots in FFB funding – 24 to date and across the spectrum of inherited retinal diseases.

What's behind this amazing progress? We take your donated dollars and, through a review process involving the field's leading researchers and clinicians, deploy them worldwide, leveraging your donation for additional investments. Give us \$100 or \$1,000 or \$25,000, and we will carefully invest that money in research that we believe will not only improve the field's understanding of how to treat retinal diseases but will also attract the larger investments required to bring those treatments to market.

Our current priority is moving more and more therapies that show promise in the lab to clinical trials to show safety and efficacy. We need your continued help to do so.

In closing I want to reiterate that fulfilling our mission to end blindness caused by inherited retinal disease takes a team. I want to thank the score of FFB researchers and clinicians who are working hard every day to find cures. I want to thank those experts who sit on FFB's Research Oversight Committee and our Scientific Advisory Board for continually lending their expertise to the effort. I want to recognize the patients who courageously participate in clinical trials. Thanks as well to our hardworking staff. And, finally, I want to again thank our donors. Without you, none of the treatment progress FFB has helped create over the last four decades would have been possible.

Sincerely,

A handwritten signature in black ink that reads "David Brint". The signature is written in a cursive, slightly stylized font.

David Brint

# CEO Report



## **Benjamin Yerxa, PhD, CEO**

I am thrilled to be writing my first CEO message as part of the Foundation's annual report. Since joining the Foundation in October, I have been continually impressed by the depth and breadth of FFB's impact on inherited retinal diseases and age-related macular degeneration research. This is truly a groundbreaking time in the search for cures, and I am proud to be part of an organization that will continue to be at the forefront of that charge.

What I've learned during my nearly 30-year career in biotechnology and drug development is what makes me so excited to be part of the Foundation's dynamic team. Simply put, FFB, with the continued support of its donors and partners, has what it takes to solve the problem of vision loss due to retinal degenerative diseases.

What's required? Funding is, of course, critical but so are strategic investment and collaborations. FFB's strategy is rooted in five key strategies:

- Steward every donor gift prudently
- Support a broad portfolio of possible treatments
- Understand how a finding in one disease area or potential therapy helps inform other studies
- Foster teamwork/partnerships with industry
- Persist

Working together, we have all these necessary ingredients and a real opportunity to rewrite the life script for people living with retinal diseases. See page eight of this report for an overview of FFB's research funding commitments during 2017. As these data demonstrate, our funding grants and investments – at research institutions worldwide – are supporting studies in many areas, including how the retina works, genetics, gene therapy, and cellular and molecular mechanisms.

Thank you for welcoming me to the team. I look forward to spending a lot of time during the coming months in the field attending FFB events, meeting our donors and chapter and walk leaders, and visiting our funded researchers. I am confident that, working together, we can make a real difference.

Sincerely,

A handwritten signature in black ink that reads "B. R. Yerxa". The signature is fluid and cursive, written over a white background.

Benjamin R. Yerxa



# 2017

## Foundation Research Funding Commitments and Investment Highlights

This year the Foundation continued its long-standing strategy of funding the most promising retinal science studies across the spectrum of these diseases. We also made several major investments in ongoing research through collaborations with industry and clinical partners.

The Foundation currently funds 75 projects at prominent laboratories and research clinical centers around the world. Listed below are a few of the significant developments and investments made by the Foundation during the past year. Following these summaries is a list of clinical trials currently underway which were made possible, in part, due to FFB support. Taken together, this growing number of clinical trials and the increasing number of FFB-industry collaborations demonstrate the ways in which FFB is helping to move treatments closer to the marketplace and to the patients who will benefit from them.

### **FDA Advisory Committee Recommends Approval of RPE65 Gene Therapy**

The most exciting news of the year was the unanimous vote by the U.S. Food and Drug Administration's Advisory Committee on Cellular, Tissue, and Gene Therapies to recommend FDA approval of voretigene neparovec. The emerging treatment, developed by Spark Therapeutics and to be marketed as Luxturna™, is for people with vision loss from Leber congenital amaurosis and retinitis pigmentosa caused by RPE65 gene mutations. The treatment delivers functional copies of the RPE65 gene directly into the retina thereby compensating for the nonfunctional, mutated copies. FFB invested \$10 million in research over two decades that made clinical trials for the gene therapy possible. At press time, the ultimate FDA decision on the treatment was expected by January 2018.

### **SparingVision Formed to Advance Sight-Saving Protein**

The development of a treatment with the potential to save vision for people with retinitis pigmentosa by slowing the progression of the disease is getting a major boost thanks to the formation of the French biotech company SparingVision, to move it into a clinical trial and out to the international marketplace. The Foundation Fighting Blindness Clinical Research Institute (FFB-CRI) made an \$8.2 million equity investment in the new company.

A spinoff of the Institut de la Vision, SparingVision was established to clinically develop and commercialize a protein known as rod-derived cone viability factor (RdCVF). The emerging, vision-saving therapy performed well in several FFB-CRI-funded lab studies at the Institut de la Vision in Paris. SparingVision's goal is to launch a clinical trial in 2019.

### **Foundation Investing in Drug to Slow Many Forms of Retinitis Pigmentosa**

Sometimes, fighting blindness means helping people save the vision they have, or at least slowing disease progression enough so they can maintain useful vision for all of their lives.

That's the idea behind a promising, emerging drug for retinitis pigmentosa (RP) known as N-acetylcysteine-amide (NACA). The Foundation Fighting Blindness Clinical Research Institute announced an investment of up to \$7.5 million to advance the potential therapy into and through a Phase 2 clinical trial. In several animal models, including previous FFB-funded lab studies of rodent models at Johns Hopkins University, NACA slowed retinal degeneration.

Nacuity Pharmaceuticals, Inc., a start-up company in Fort Worth, Texas, owns the rights to NACA for ophthalmology and will be



developing the drug with support from FFB-CRI. As part of its agreement with Nacuity, upon commercialization of NACA, FFB-CRI will be entitled to royalty payments from future NACA sales.

### FFB-CRI Launches Natural History Study for People with USH2A Mutations

USH2A is a target for retinal-disease researchers because mutations in the gene are the most common cause of Usher syndrome type 2, which causes combined vision loss from retinitis pigmentosa (RP) and hearing loss from inner ear dysfunction. Also, USH2A mutations are a leading cause of RP without hearing loss (i.e., nonsyndromic).

A major challenge in providing prognoses for USH2A patients – and designing clinical trials for potential therapies – is the wide variability in the severity and rate of progression of the disease and its symptoms. Researchers have identified hundreds of USH2A mutations – misspellings in the patients' genetic code. Some of these defects lead to RP only. Others cause Usher syndrome.

To gain a better understanding of how USH2A mutations affect the severity and progression of vision loss, the FFB-CRI has launched a four-year, \$8 million natural history study of 120 people with USH2A mutations. The study – known as RUSH2A (“R” stands for “rate of progression”) – began in spring 2017 and will take place at about 20 clinical sites around the world. RUSH2A investigators are using a variety of technologies to monitor changes in vision and retinal structure to document and analyze disease progression.

The results of RUSH2A will help USH2A therapy developers, including companies and research institutes, better design clinical trials by enabling them to enroll the patients who are most likely to respond to treatment. It may also help determine clinical trial sensitive and precise outcome measures to quickly determine if a therapy is working to save vision.

## Clinical Trials for Emerging Retinal Degenerative Disease Therapies

### Select Trials as of Fall 2017

Thanks to research advances made possible by the Foundation Fighting Blindness and research-funding organizations around the world, more clinical trials for retinal-disease therapies are underway than ever before. The following graphic is a snapshot of many of these studies. While not all these potential treatments will gain regulatory approval, the momentum in clinical development provides real promise for saving and restoring vision for everyone affected.

| Type | Disease Target    | Emerging Therapy              | Company                         | Phase     | Trial Sites   |
|------|-------------------|-------------------------------|---------------------------------|-----------|---|
| Cell | Dry AMD           | RPE cells on scaffold         | Regenerative Patch Technologies | Phase 1/2 | Five sites in Southern California   |
| Cell | Dry AMD           | RPE cells                     | Cell Cure                       | Phase 1/2 | <ul style="list-style-type: none"> <li>• Two U.S. sites</li> <li>• Four Israeli sites</li> </ul>                                  |
| Cell | RP                | Retinal progenitor cells      | jCyte                           | Phase 2   | <ul style="list-style-type: none"> <li>• University of California, Irvine</li> <li>• Retina-Vitreous Associates (L.A.)</li> </ul> |
| Cell | RP                | Retinal progenitor cells      | ReNeuron                        | Phase 1/2 | Massachusetts Eye and Ear Infirmary   |
| Drug | Dry AMD           | Complement factor 3 inhibitor | Apellis                         | Phase 2   | Thirty-five sites in U.S., Australia, New Zealand   |
| Drug | Stargardt disease | Emixustat hydrochloride       | Acucela                         | Phase 2   | Retina Foundation of the Southwest (Dallas)   |
| Drug | Stargardt disease | Deuterated vitamin A          | Alkeus                          | Phase 2   | Seven U.S. Sites  |
| Gene | Achromatopsia     | CNGA3 gene therapy            | AGTC                            | Phase 1/2 | <ul style="list-style-type: none"> <li>• Five U.S. sites</li> <li>• One Israeli site</li> </ul>                                   |

|      |                   |  |                              |                   |  |
|------|-------------------|--|------------------------------|-------------------|--|
| Gene | Achromatopsia     | CNGB3 gene therapy   | AGTC                         | Phase 1/2         | Five U.S. sites  |
| Gene | Achromatopsia     | CNGB3 gene therapy   | MeiraGTx                     | Phase 1/2         | Moorfields Eye Hospital (UK)   |
| Gene | Achromatopsia     | CNGA3 gene therapy   | University Hospital Tübingen | Phase 1/2         | University Hospital Tübingen (Germany)   |
| Gene | Choroideremia     | REP1 gene therapy  | Bascom Palmer                | Phase 2           | Bascom Palmer (Miami)  |
| Gene | Choroideremia     | REP1 gene therapy  | Nightstar                    | Phase 2           | <ul style="list-style-type: none"> <li>• Moorfields Eye Hospital (UK)</li> <li>• Oxford University (UK)</li> </ul>   |
| Gene | Choroideremia     | REP1 gene therapy  | Spark                        | Phase 1/2         | <ul style="list-style-type: none"> <li>• Children's Hospital of Philadelphia</li> <li>• University of Pennsylvania</li> <li>• Massachusetts Eye &amp; Ear Infirmary</li> </ul> |
| Gene | Choroideremia     | REP1 gene therapy  | University Hospital Tübingen | Phase 2           | University Hospital Tübingen (Germany)   |
| Gene | LCA               | Antisense oligonucleotide for CEP290 (c.2991+1655A>G mutation) | ProQR                        | Phase 1/2         | <ul style="list-style-type: none"> <li>• University of Iowa</li> <li>• University of Pennsylvania</li> <li>• Ghent University Hospital (Belgium)</li> </ul>                    |
| Gene | LCA and RP        | RPE65 gene therapy   | Spark                        | Completed Phase 3 | <ul style="list-style-type: none"> <li>• Children's Hospital of Philadelphia</li> <li>• University of Iowa</li> </ul>  |
| Gene | Retinoschisis     | RS1 gene therapy   | AGTC                         | Phase 1/2         | Eight U.S. sites   |
| Gene | Retinoschisis     | RS1 gene therapy   | National Eye Institute       | Phase 1/2         | National Eye Institute (Bethesda)  |
| Gene | RP (Recessive)    | PDE6B gene therapy   | Horama                       | Phase 1/2         | Nantes University Hospital (France)  |
| Gene | RP                | Optogenetic gene therapy                                       | Allergan                     | Phase 1/2         | Retina Foundation of the Southwest (Dallas)  |
| Gene | RP (X-Linked)     | RPGR gene therapy  | MeiraGTx                     | Phase 1/2         | Moorfields Eye Hospital (UK)   |
| Gene | RP (X-Linked)     | RPGR gene therapy  | Nightstar                    | Phase 1/2         | <ul style="list-style-type: none"> <li>• Manchester Royal Eye Hospital (UK)</li> <li>• Oxford Eye Hospital (UK)</li> </ul>   |
| Gene | Stargardt disease | ABCA4 gene therapy   | Sanofi                       | Phase 1/2         | <ul style="list-style-type: none"> <li>• Three U.S. sites</li> <li>• One French site</li> </ul>  |
| Gene | Usher type 1B     | MYO7A gene therapy   | Sanofi                       | Phase 1/2         | <ul style="list-style-type: none"> <li>• Oregon Health &amp; Science University</li> <li>• Hôpital des Quinze-Vingts (France)</li> </ul>                                       |

**Notes:**

- Visit [www.ClinicalTrials.gov](http://www.ClinicalTrials.gov) for additional trial information including study contacts.
- The list is for select trials – not all clinical trials for retinal diseases are included.
- Always consult your physician before trying a new therapy or considering a clinical trial.

# Treasurer's Report



## Haynes Lea, *Treasurer*

I am pleased to provide you the statement of activities and financial position for the Foundation Fighting Blindness fiscal year ending June 30, 2017.

We are especially grateful for the generous support of our donors. Their generosity has put the Foundation in a strong financial position to seed the important early research that will discover the next cure, maintain high levels of clinical research funding, and respond to breakthrough opportunities as they arise.

Our stewardship of the substantial funds raised through the Gordon and Llura Gund Family Challenge is guided by our strategic plan.

Developed by FFB's Research Oversight Committee, the strategic plan calls for the investment of \$20 million in translational and proof-of-concept research each year for the next five years. Two projects initiated this past year involved commitments of up to \$7.5 million each, leveraged with funds from other investors, to get patients into Phase 2 clinical trials. We are beginning to see grants made decades ago culminate in FDA applications for approval of actual treatments. In addition, thanks to our donors, we are now able to invest at dollar levels that can push these projects through to the clinic.

The application of nonprofit accounting principles to our financial statements creates two anomalies that merit additional explanation. These result from a combination of the pace of funding research commitments and the great success of the Gund Family Challenge in generating an unprecedented level of multiyear pledges.

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Our audited financial statements indicate we have future obligations for grant payments of only \$10 million, which suggests a relatively high level of net assets. In reality, we have binding commitments and reserves for identified, milestone-based research spending totaling \$57.5 million. The funding for the additional \$47.5 million in grant commitments and clinical trial-related costs is subject to certain scientific milestones, however; and under generally accepted accounting principles, these obligations may not be reflected as liabilities on our balance sheet until the milestones are met. If any milestones are not met, the funds committed to that research will be redeployed into other research worthy of our support.

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Meanwhile, the Gund Family Challenge generated substantial pledges payable over multiple years. Accounting rules require that we record all pledged revenue in the years the pledges are made rather than as the pledges are actually paid or as research projects are funded. *As a result, the funding of research projects creates a deficit for the current fiscal year even when the projects are funded out of contributions collected during the same year.* As additional information, we have presented on the following page our statement of activities and financial position based on a modified accrual basis to reflect campaign cash intake and research outlays and commitments.

In sum, the Foundation has the financial resources and the strategic partnerships within the inherited retinal disease research community to continue to be the unparalleled leader driving cures to the clinic and the marketplace. With the continued generosity of our donors, the vision and expertise of our research team, and the energy and leadership of our new chief executive officer, we are excited to be able to make the significant investments necessary to fulfill our mission.

With heartfelt thanks to all our donors, volunteers, staff, and researchers,

A handwritten signature in black ink that reads "Haynes P. Lea". The signature is fluid and cursive.

Haynes P. Lea



## Unaudited, Modified Accrual Basis

### Statement of Activities

#### REVENUE AND SUPPORT

|                                    |                     |
|------------------------------------|---------------------|
| Contributions.....                 | 28,237,000*         |
| Special events, net of direct..... | 7,512,000           |
| Bequests .....                     | 3,655,000           |
| Other revenue .....                | 658,000             |
| <b>Total Revenue .....</b>         | <b>\$40,062,000</b> |

#### EXPENSES

|                                |                     |
|--------------------------------|---------------------|
| Research .....                 | 27,697,000*         |
| Public health information..... | 1,609,000           |
| Management.....                | 2,842,000           |
| Fundraising .....              | 7,223,000           |
| <b>Total Expenses .....</b>    | <b>\$39,371,000</b> |

**Total Change in Net Assets .....** \$691,000\*

### Statement of Financial Position

#### ASSETS

|                              |                      |
|------------------------------|----------------------|
| Cash and investments .....   | 106,919,000          |
| Other assets.....            | 2,397,000*           |
| Trusts and other funds ..... | 7,848,000            |
| Fixed assets, net.....       | 1,558,000            |
| <b>Total Assets .....</b>    | <b>\$118,722,000</b> |

#### LIABILITIES

|  |                     |
|--|---------------------|
| Accounts payable and accrued liabilities.....  | 806,000             |
| Research grants payable.....                   | 58,168,000*         |
| Deferred revenue .....                         | 1,348,000           |
| Liabilities under trusts and other funds ..... | 1,668,000           |
| <b>Total Liabilities .....</b>                 | <b>\$61,990,000</b> |

#### NET ASSETS

|   |                      |
|---|----------------------|
| Total net assets .....                        | 56,732,000*          |
| <b>Total Liabilities and Net Assets .....</b> | <b>\$118,722,000</b> |

\* Does not reflect audited results in accordance with Generally Accepted Accounting Principles. Full audited financial statements are available at [www.FightBlindness.org](http://www.FightBlindness.org).

## Year Ahead— Target Spending Allocations

**70%** Research Including Grants



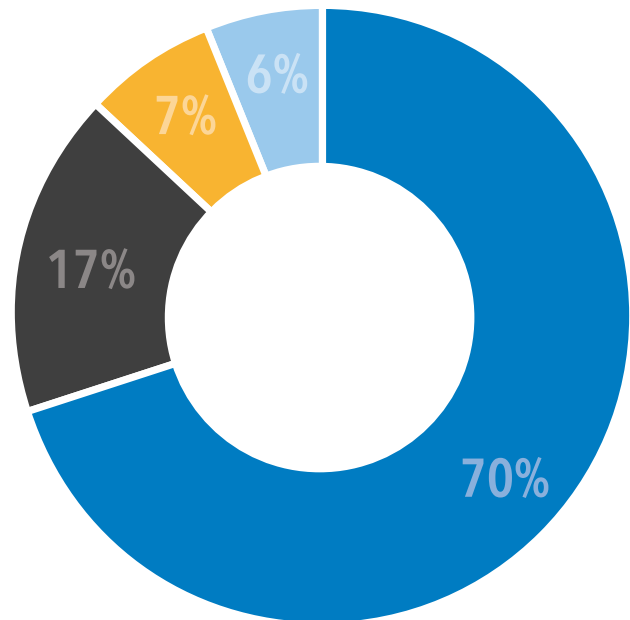
**17%** Fundraising



**7%** Public Health Education



**6%** Administration



# 2017 Research Grants

## 2017 Research Investments

In its focused pursuit of preventions, treatments, and cures for the entire spectrum of retinal degenerative diseases, the Foundation evaluates and selects for support a diverse research portfolio. That portfolio is focused on six priority areas: genetics, gene therapy, the cellular mechanisms of retinal diseases, clinical structure and functional relationships, novel medical therapy, and regenerative medicine.

## 2017 New Commitments

Research Center grant funding ..... 4,991,888

Individual Investigator grant funding ..... 3,370,795

Alan Laties Career Development grant funding ..... 1,635,000

Clinical Research Institute clinical studies and grant funding ..... 15,000,000

**Total 2017 funding: .....\$24,997,683**

For a complete list of all 2017 Foundation Fighting Blindness grant recipients, please visit: [www.blindness.org/funded-grants](http://www.blindness.org/funded-grants).

**4%** Clinical Structure and Functional Relationships



**6%** Genetics



**2%** Gene Therapy



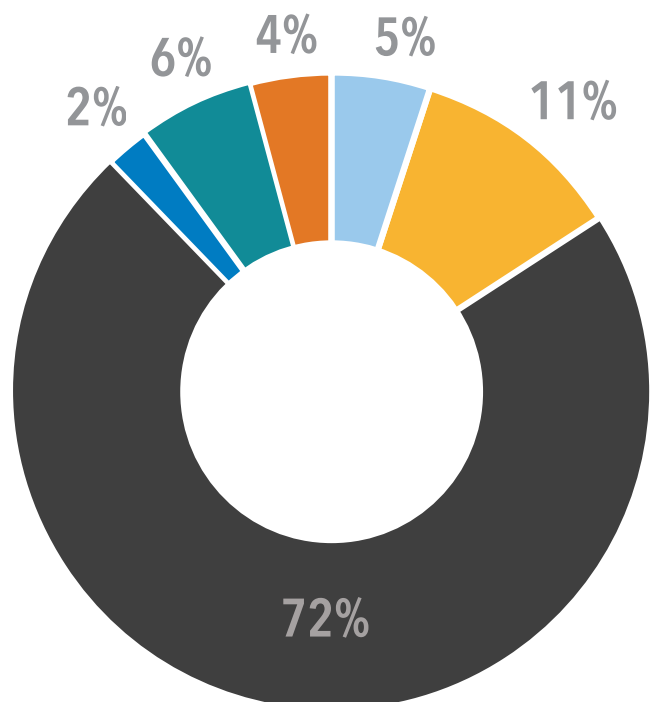
**72%** Novel Medical Therapy



**11%** Cellular and Molecular Mechanisms



**5%** Regenerative Medicine



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