Genotype-Tissue Expression Project (GTEx)

The GTEx Project aims to provide comprehensive, high-quality genomic and transcriptomic data for a representative sample of healthy human tissues and organs. This project is a large-scale effort to create a comprehensive resource of genomic data for human tissues, allowing researchers to study the relationship between genetic variation and gene expression in different tissues. The GTEx Project is a collaborative effort involving multiple institutions and researchers, and it involves the use of tissue samples collected through organ donation. The goal is to provide a detailed understanding of how genetic variation affects gene expression and to identify potential disease mechanisms.

From Bench to Bedside: Helping CF Patients Breathe Easier

Captopril was used in a clinical trial of patients with cystic fibrosis. The trial involved a small sample size, but the results showed promise. The trial was sponsored by the National Heart, Lung, and Blood Institute (NHLBI), and the data was used to support the development of new treatments for cystic fibrosis. The use of captopril in this trial demonstrated the potential of using tissue samples from organ donors to study disease mechanisms and develop new therapies.

National Disease Research Interchange (NDRI)

NDRI is a non-profit organization that provides researchers with access to human tissue samples for scientific research. NDRI collects tissue samples from organ donors and provides them to researchers for use in scientific studies. The organization has a mission to advance medical research through organ and tissue donation. NDRI is committed to ensuring that the tissue samples are used ethically and responsibly, and it provides researchers with the tools and resources they need to conduct high-quality research.

NDRI Board of Directors

The NDRI Board of Directors is comprised of a group of experienced professionals from various fields, including medicine, law, and business. The board is responsible for overseeing the organization’s mission and ensuring that its activities align with its goals. The board members bring a unique set of skills and perspectives to the organization, and they work together to ensure that NDRI continues to provide high-quality tissue samples to researchers around the world.

**Strategic Projects: Bringing New Treatments to Patients Faster**

- **Genotype-Tissue Expression Project (GTEx)**
  - NDRI’s Genotype-Tissue Expression (GTEx) Project will help researchers identify genetic variants that may affect gene expression and disease susceptibility. The project involves collecting and analyzing tissue samples from organ donors to create a comprehensive resource for genomics and transcriptomics.
  - The GTEx Project will also help researchers understand how genetic variation affects gene expression in different tissues and organs. This knowledge can be used to develop new treatments for diseases and conditions that are difficult to treat.

- **LungMAP**
  - The LungMAP initiative is a major initiative aimed at critically evaluating the processes of normal lung growth and development. Research using lungs provided by NDRI donors will help inform the development of novel treatments and therapies.
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- **Treatment for LAM**
  - The Strategic Lungs for Early Childhood program is a major initiative aimed at critically evaluating the processes of normal lung growth and development. Research using lungs provided by NDRI donors will help inform the development of novel treatments and therapies.

- **Treatment for CF**
  - The Cystic Fibrosis drug, VX-809, has been approved by the FDA in 2012 for people ages 8 and older with the G551D mutation. Vertex researchers have also developed the pipeline Cystic Fibrosis drug, VX-809.
  - Using lungs recovered from Cystic Fibrosis patients who received lung transplants, researchers developed the first drug that targets the underlying cause of Cystic Fibrosis. Kalydeco® is an oral medication developed by Vertex and approved by the FDA in 2012 for people ages 6 and older with the G551D mutation. Vertex researchers have also developed the pipeline Cystic Fibrosis drug, VX-809.

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SIROLIMUS IS NOW USED TO TREAT LAM WORLDWIDE.

IMPROVED QUALITY OF LIFE IN PATIENTS WITH MODERATE TO SEVERE LAM.

A Clinical trial, which found that the drug stabilized lung function and improved quality of life in patients with moderate to severe LAM, was the first study to find that targeting mTOR (mammalian target of rapamycin) improved outcomes in LAM. In this study, researchers at the University of Pennsylvania School of Medicine led to a clinical trial, which found that the drug stabilized lung function and improved quality of life in patients with moderate to severe LAM. Researchers have also developed the mTOR inhibitor everolimus, which is approved for treatment of advanced renal cell carcinoma and is currently undergoing clinical trials in combination with immunosuppressive agents for the treatment of LAM.

LUNGMAP

NIH’s Molecular Atlas of Lung Development (program, or LungMAP) is a major initiative aimed at critically evaluating the processes of normal lung growth and development. Research using lungs provided by NDRI at the East Tennessee Children’s Hospital. Kalydeco®, a new Cystic Fibrosis treatment, was developed by Vertex using lungs recovered from Cystic Fibrosis patients who received lung transplants. Researchers developed the first drug that targets the underlying cause of Cystic Fibrosis. Kalydeco® is an oral medication developed by Vertex and approved by the FDA in 2012 for people ages 6 and older with the G551D mutation. Vertex researchers have also developed the pipeline Cystic Fibrosis drug VX-809.

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Current Federal Funding
National Institutes of Health
• National Eye Institute
• National Heart, Lung and Blood Institute
• National Institute of Arthritis and Musculoskeletal and Skin Diseases
• National Institute of Allergy and Infectious Diseases
• National Institute of Allergy and Infectious Diseases
• National Institute of Neurological Disorders and Stroke
• National Institute of Mental Health
• Office of the Director

Advancing medical research through organ and tissue donation

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Human Tissues and Organs for Research (HTOR) Program

The HTOR program provides researchers with fresh and preserved human tissue, organs, and disease specimens. Its key features include:
- Fresh specimens from organ donors
- Preserved tissue in standard, FFPE, OCT, and whole eye sections
- A tiered cancer program
- Collection of normal tissues with a low molecular analysis preservation interval suitable for exacting molecular analysis
- A comprehensive catalog of human tissues

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San Francisco
Takeda Pharmaceutical Company
Senior Scientist

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Empowering Research and Discovery

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For patients and families, the opportunity to donate for research that may lead to new treatments or discovers offers comfort and hope.

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Brain and Neurologic Tissue

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Preclinical Research

Andrew Simmons, PhD

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“One of the main challenges in pharmaceutical

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Sarah Gray

Bereaved families need a way to

donate Thomas’s organs and tissue to research.

Five years ago Sarah gave birth to twin boys Callum and Thomas. Thomas died one day after his birthday due to a rare birth defect called Potter syndrome. Sarah and Ross didn’t know how to provide their son with the best care that he needed. The Grays were then introduced to the Joslin Medalists Program.

Joslin Medalists Program:

Voluntary Health Organizations to facilitate donation for research.

National Rare Disease Partnership of Voluntary Health Organizations:

NDRI establishes partnerships with Rare Disease

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NDRI Supports Breakthrough Research

NDRI: • Databases contain more than 3.3 million human biospecimens each year • Offers an Online Biospecimen Catalogue (OBC) with more than 7,000 fixed and frozen biospecimens • Establishes research partnerships with for-profit and non-profit organizations • Accepts biospecimens that are procured by NDRI and NDRI contractors • Works with more than 300 large procurement organizations, tissue and eye banks, hospitals, and voluntary health organizations

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Treatment for Cystic Fibrosis

Using lungs recovered from Cystic Fibrosis patients who received lung transplants, researchers developed the first drug that targets the underlying cause of Cystic Fibrosis. Kalydeco® is an oral medication developed by Vertex and approved by the FDA in 2012 for people ages 6 and older with the G551D mutation. Vertex researchers have also developed the pipeline Cystic Fibrosis drug, VX-809.

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Preclinical testing of the drug Sirolimus, using LAM cells from NDRI by MD Anderson, showed that Sirolimus could stabilize lung function and may slow disease progression. Research using lungs provided by NDRI is a major initiative aimed at critically evaluating the processes of normal lung growth and development. Research using lungs provided by NDRI will aid in the understanding of serious and often fatal lung diseases that develop during early childhood, and help inform the development of novel treatments and therapies.

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