### **NORDP Research Development Conference**

Research Development Strategy: Designing a De Novo Institute With Numerous Degrees of Freedom

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# Introduction



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## **Pediatric Genomics**



### **Selected Themes**





## **Case Study:**

Rady Pediatric Genomics and Systems Medicine Institute

No RFA or RFP guided the development of the institute. Instead, a deliberate process was undertaken to design the institute de novo.

#### **Overview**

- » Story
- » Similarities and differences versus more traditional research development
- » Thought and discussion: research development challenges and approaches



# **Institute Launch**



## **August 2014 Press Release**

### Rady Children's to Establish Pediatric Genomics and Systems Medicine Institute

Ernest Rady Family Pledges \$120 Million to Support Institute

San Diego – August 4, 2014 – Rady Children's Hospital-San Diego has taken a major step forward in the research of childhood diseases with the establishment of the Rady Pediatric Genomics and Systems Medicine Institute at Rady Children's. Ernest Rady and family have made yet another extraordinary investment in the health and wellbeing of children by pledging \$120 million to support pediatric research and innovation at the Institute. The gift is the largest donation ever made to Rady Children's Hospital Foundation. Rady Children's Board of Trustees has committed an additional \$40 million in funding to support the Institute.

Source: http://www.rchsd.org/about-us/newsroom/press-releases/rady-childrens-to-establish-pediatricgenomics-and-systems-medicine-institute.



## August 2014 Press Release (continued)

"After more than one and half years of evaluating the design and mission of an Institute at Rady Children's, this Institute will assemble a team of world class scientists, researchers and clinicians who will focus their talents on preventing, diagnosing, treating and curing childhood disease through genomics and systems medicine research.

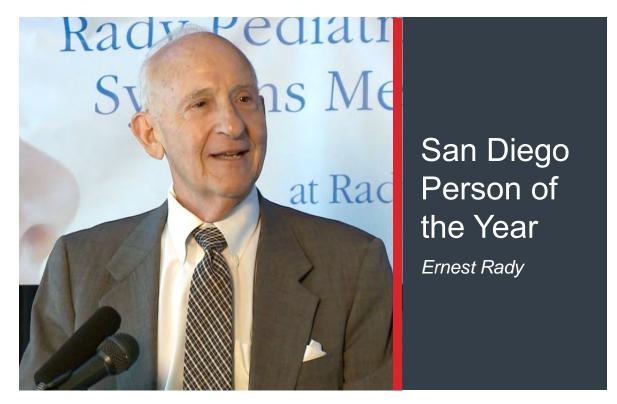
The Institute will work closely with UC San Diego and establish relationships with other academic and research institutions, companies involved in genomics research and other children's hospitals to advance the mission of the Institute." — David Hale, Chairman of the Board

Source: http://www.rchsd.org/about-us/newsroom/press-releases/rady-childrens-toestablish-pediatric-genomics-and-systems-medicine-institute. Emphasis added.



## San Diego Person of the Year

"It was one of the most generous acts of philanthropy ever in San Diego and raised his total contributions to the hospital to an astounding \$180 million."



Source: http://www.utsandiego.com/news/2015/jan/01/san-diego-person-of-the-year-ernest-rady.



# **Environmental Context**



## **Rady Children's Hospital**

Rady Children's Hospital-San Diego is the region's pediatric medical center serving San Diego, Imperial, and southern Riverside counties.

### **Hospital Snapshot**

- » 520-bed pediatric care facility
- » Largest children's hospital in California (based on admissions)
- » Sixth-largest children's hospital in the country
- » Provider of care to 88% of region's children
- » Region's only designated pediatric trauma center
- » Ranked by U.S. News & World Report among the best children's hospitals in the nation in all 10 pediatric specialties the magazine surveyed

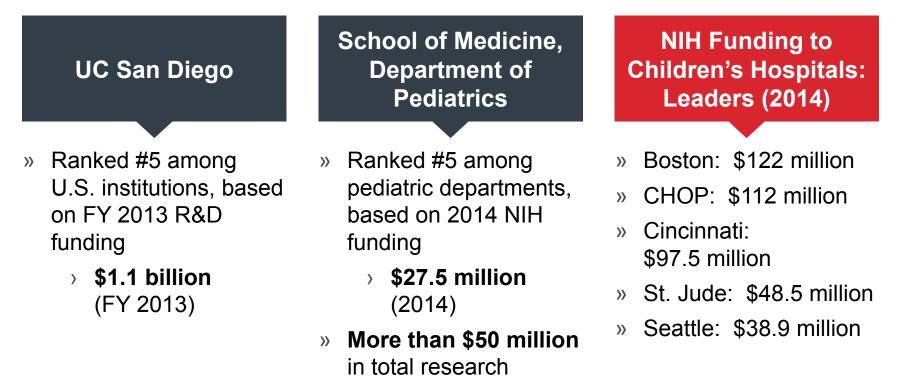


Rady Children's does not, however, have its own robust research enterprise.



## **UC** San Diego

Rady Children's and UC San Diego have been affiliated since 2001. The agreement spans pediatric patient care, research, education, and community service programs.



funding (FY 2013)

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## **Independent Research Institutes**

The Torrey Pines area of La Jolla/San Diego is home to a concentrated array of leading independent research institutes.





## **Biotech Industry**

"San Diego has become the human genome research capital in America." — Former President Bill Clinton



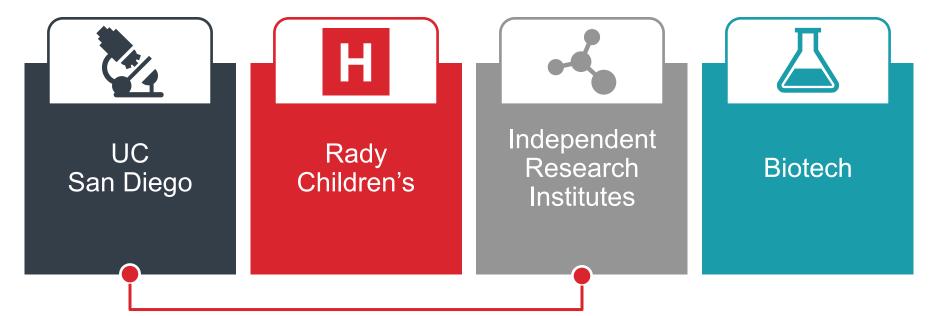
Sources: CNBC's "Closing Bell" program, June 5, 2012; Biocom map of biotech firms.



## **Innovation Ecosystem**

"Best of Both Worlds"

The area's innovation ecosystem—in "-omics" and related research—stretches from a large public university system to established and start-up biotech firms.



Nationally, many independent research institutions are under pressure and exploring partnerships with research universities and their more diversified revenue streams.



## **Scientific Context**

Researchers are actively exploring the interface between pediatric medicine and a range of advanced research approaches and tools— including genomics, proteomics, metabolomics, bioinformatics, and systems analysis.

- » "Biomedical research and the practice of medicine, separately and together, are reaching an inflection point: the capacity for description and for collecting data, is expanding dramatically, but the efficiency of compiling, organizing, manipulating these data—and extracting true understanding of fundamental biological processes, and insights into human health and disease, from them—has not kept pace."1
- » "[T]here is a growing shortfall: without better integration of information both within and between research and medicine, an increasing wealth of information is left unused."1
- » "[M]edical genomics, based on recent advances in high-throughput experimental and computational technologies, is evolving in the context of systems biology into a more prospective systems medicine."<sup>2</sup>

<sup>&</sup>lt;sup>2</sup> Source: C. Auffray, Z. Chen, and L. Hood, "Systems medicine: the future of medical genomics and healthcare," *Genome Medicine*, 1:2; 2009. Emphasis added.



<sup>&</sup>lt;sup>1</sup> Source: National Research Council, *Toward Precision Medicine: Building a Knowledge Network for Biomedical Research and a New Taxonomy of Disease,* The National Academies Press, 2011. Emphasis added.

# Institute Design



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## **Design Process**



A business plan served as a concrete, iterative document in which to organize and present the design elements of the evolving institute.



## **Competitive Assessment**

An extensive competitive assessment helped influence design decisions along dimensions such as organization, governance, university linkages, faculty recruitment, strategic research investments, and approaches to administration and operations.



## **Design Components**

Characteristics

Institute design was influenced by best practices and lessons learned from successful independent research institutes, universities, hospitals, and affiliations between entities.

### **Selected Institute Design Characteristics**

- » Research focus, with targeted scientific identity and investments
- » Operational agility, including the efficient negotiation of research contracts and unique partnership opportunities
- » Financial and business acumen, including strong focus on the costs and revenues of operations
- » High research productivity expectations
- » Access to UC San Diego graduate students and postdocs
- » Access to UC San Diego core facilities and other shared research infrastructure
- » Faculty appointments used as key recruitment tool
- » Utilizing university administrative and operations capabilities where economics of scale or scope exist—allowing for the focus of institute investments and attention on research productivity and translation

### Design Components Goals

- » Visibility Develop a highly respected organization that positively impacts Rady Children's overall and research brands.
- » Agility Design an organization that possesses the nimbleness to rapidly respond to opportunities and collaborate with diverse research and clinical partners.
- » Environment Craft a unique research environment that attracts the strongest researchers in genomics and systems medicine, nationally and internationally, to focus their talents and efforts on addressing childhood diseases.
- » Research Focus Focus on a small number of specific disease areas and systems medicine approaches to build a critical mass of investigators and generate exceptional discoveries.
- » Research Capacity, Competitiveness, and Ranking Contribute to significantly developing these areas at Rady Children's.
- » Research Translation Effectively translate research discoveries into better patient diagnosis and treatment.



## **Design Components**

Vision

This internal "what is the institute trying to do?" graphic was helpful in achieving and maintaining focus and direction during the design process.



ASSEMBLE world-class scientists and clinicians into a targeted, visible environment that combines a unique patient population with a leading academic research university. EQUIP these researchers with a well-designed, discoveryenabling shared research infrastructure.



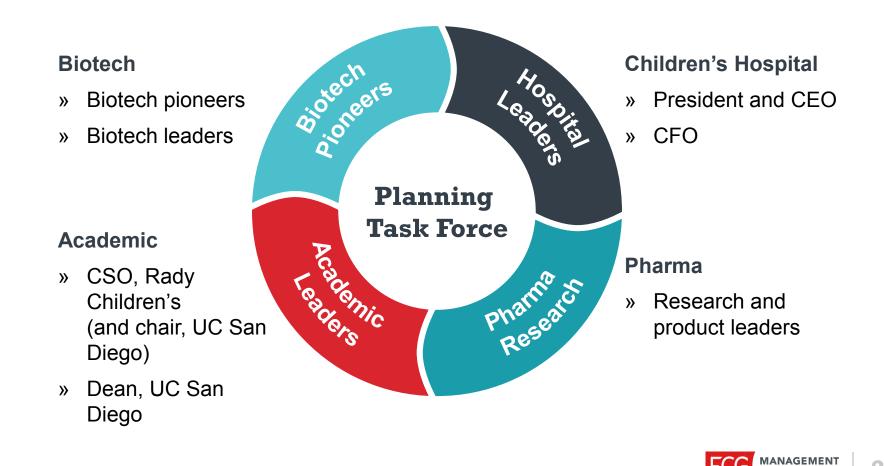


ACCELERATE the translation of research discoveries into childhood disease prevention, diagnosis, treatment, and cure. FOCUS these researchers' talents on solving childhood diseases using systems medicine approaches (incl. genomics, proteomics, and epigenomics).



## **Committee Interaction**

A diverse institute Planning Task Force explored areas including research competitiveness, operational agility, patient care improvements, reputation, and partnerships.



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## **Design Elements/Decisions**

#### ORGANIZATION

- » Legal structure
- » Governance
- » Leadership
- » Employment
- » Faculty appointment
- » Physical location

### OPERATIONS

- » Accounting and finance
  - » Development and fundraising
  - » Human resources
  - » IT
  - » Intellectual property management
  - » Legal
  - » Marketing and communications
- » Research administration



## Design Elements/Decisions (continued)

### RESEARCH STRATEGY

- » Scientific focus areas
- » Strategic research investments:
  - Faculty recruitment/ engagement
  - Shared research infrastructure:
    - > Biorepository
    - > IT infrastructure
    - > Clinical informatics

### PARTNERSHIPS

» Approach/strategy

### FINANCIAL PRO FORMA

- » Investments
- » Assumptions
- » Expectations



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## **Takeaways**



Research development professionals can learn from the study of de novo research center and institute design.

For organizations involved in de novo design, learnings from traditional research development are valuable.



There are of other examples of de novo design—big and small—such as the following:

 The University of Chicago's Institute for Molecular Engineering (IME)



- IME was established in 2011 in partnership with Argonne National Laboratory.
- With an organizational structure that transcends traditional boundaries, IME boasts the unique status of both an academic unit and an interdisciplinary research institute.

Source: http://ime.uchicago.edu.





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