





Survey To Assess Research Satisfaction at Stanford (STARS)

Stanford University



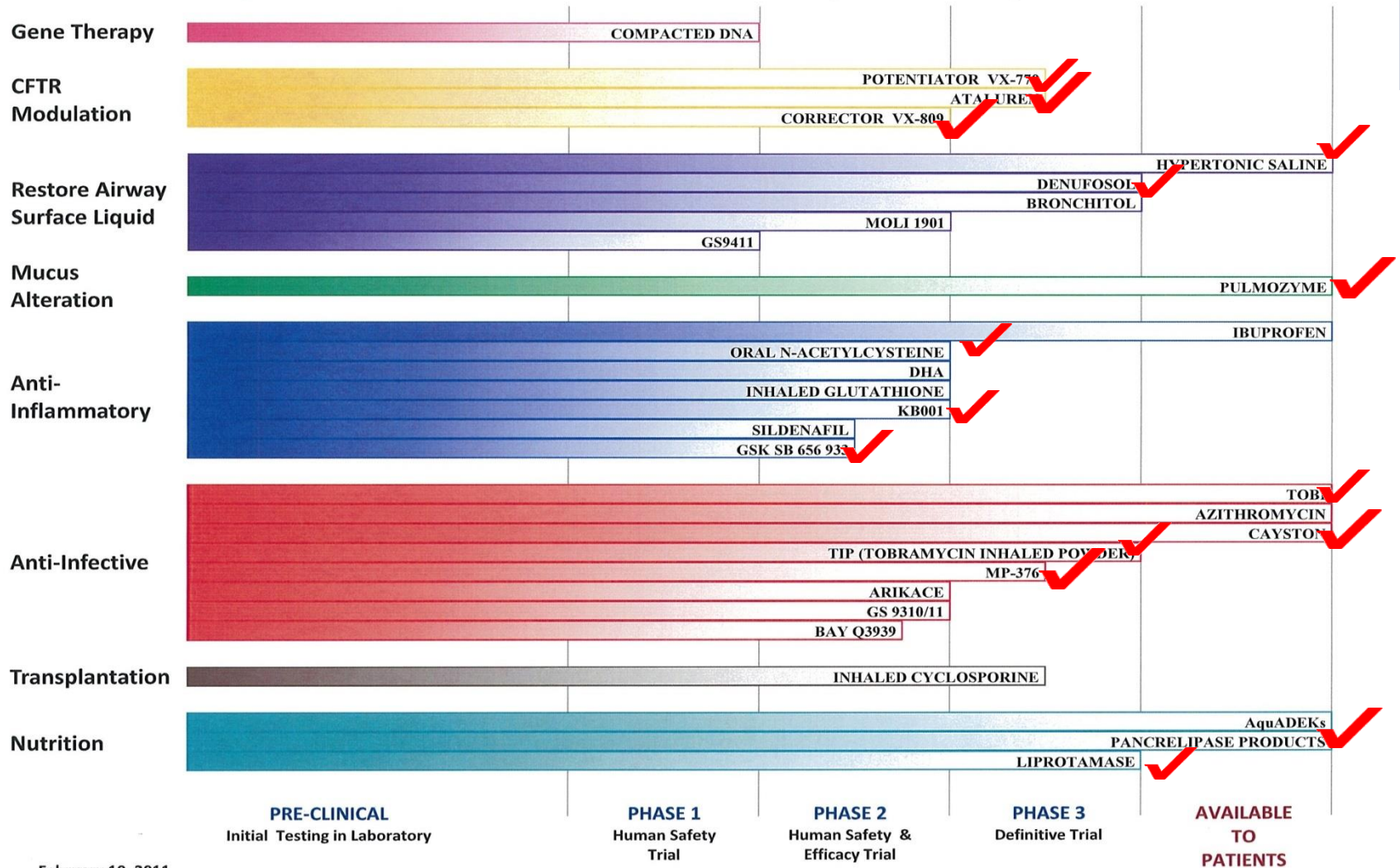
**Davies, Zoe; Dunn, Colleen; Hernandez,
Cathy; Zirbes, Jacquelyn; Milla, Carlos;
Moss, Richard.**



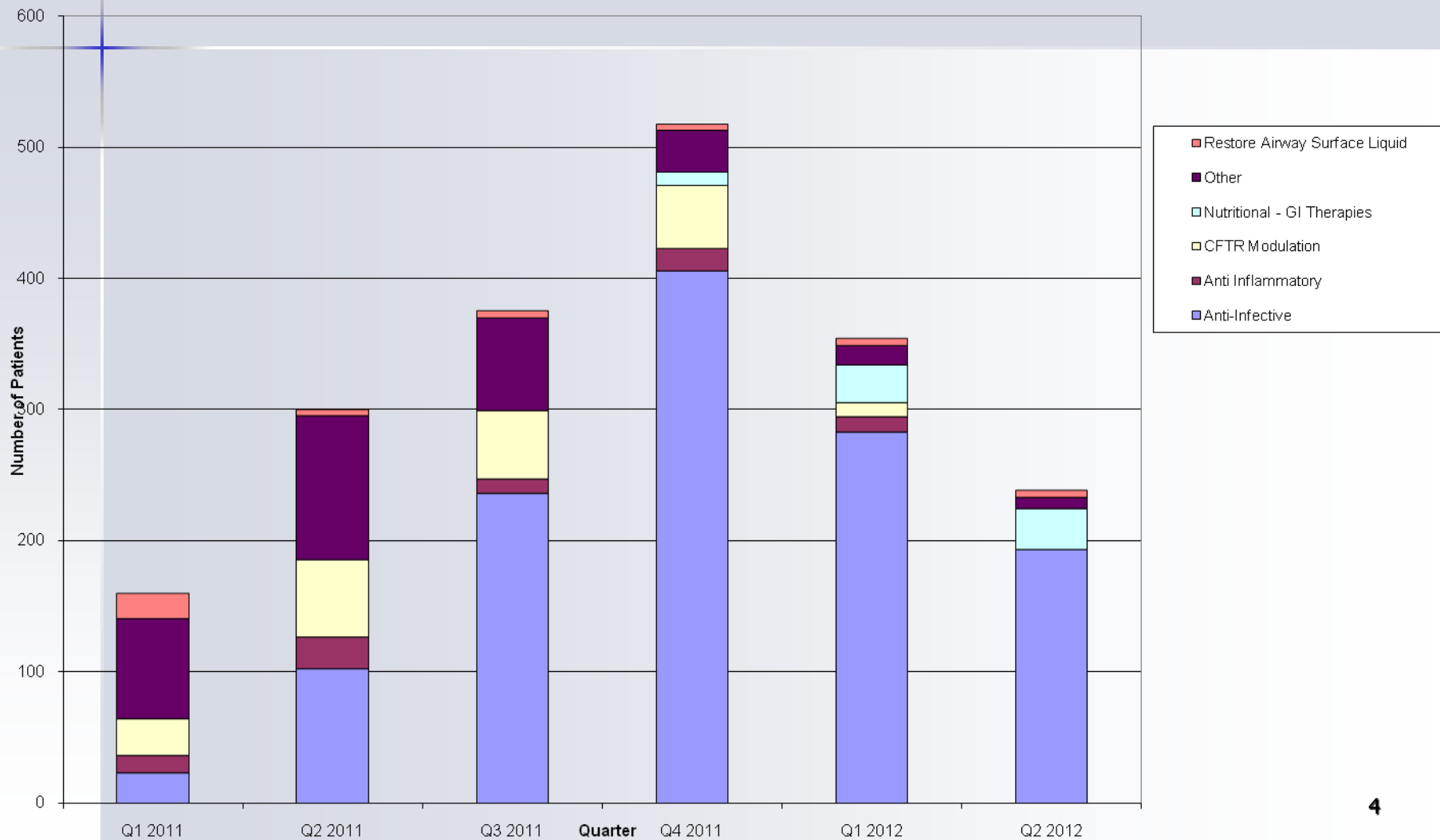
Therapeutics Development Network

- **Established in 1998**
- **7 sites**
- **1999 - Stanford**
- **2009 - 77 total**
- **Translational Research Center**
 - **12 sites**

Cystic Fibrosis Foundation Therapeutics Pipeline



Current Projections



Background Information

- Seasoned research team
- Good reputation
- Mentors
- What's our secret?
- How can we improve?

Success Hypothesis:

**Participants enjoy
their research
experience**

Why?

- Relationship
- Close follow up
- Easy access to the team
- Early access to drugs
- Altruism
- Money

Developed a questionnaire

- 28 questions
- 5 categories:
 - Overall Research Experience
 - Research Process
 - Research Procedures
 - Research Environment
 - RC Professionalism
- Several open ended questions
- General comments



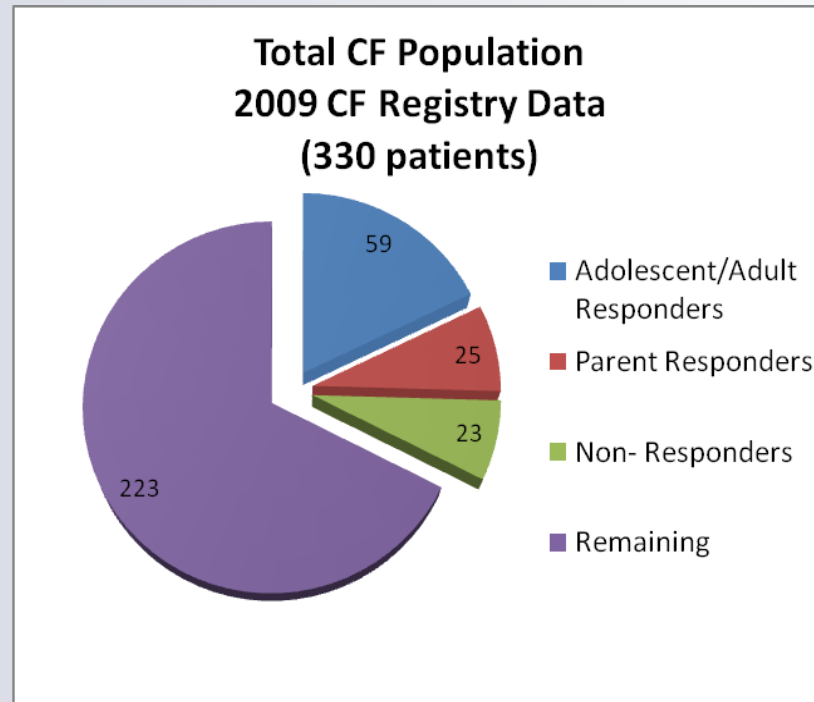
Stanford Database Search:

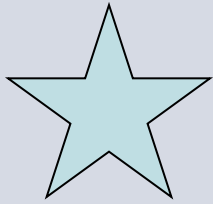


330 Stanford CF patients

107 patients eligible to participate

- 84 completed
 - 25 parent, 59 adolescent/adult
- 23 unavailable





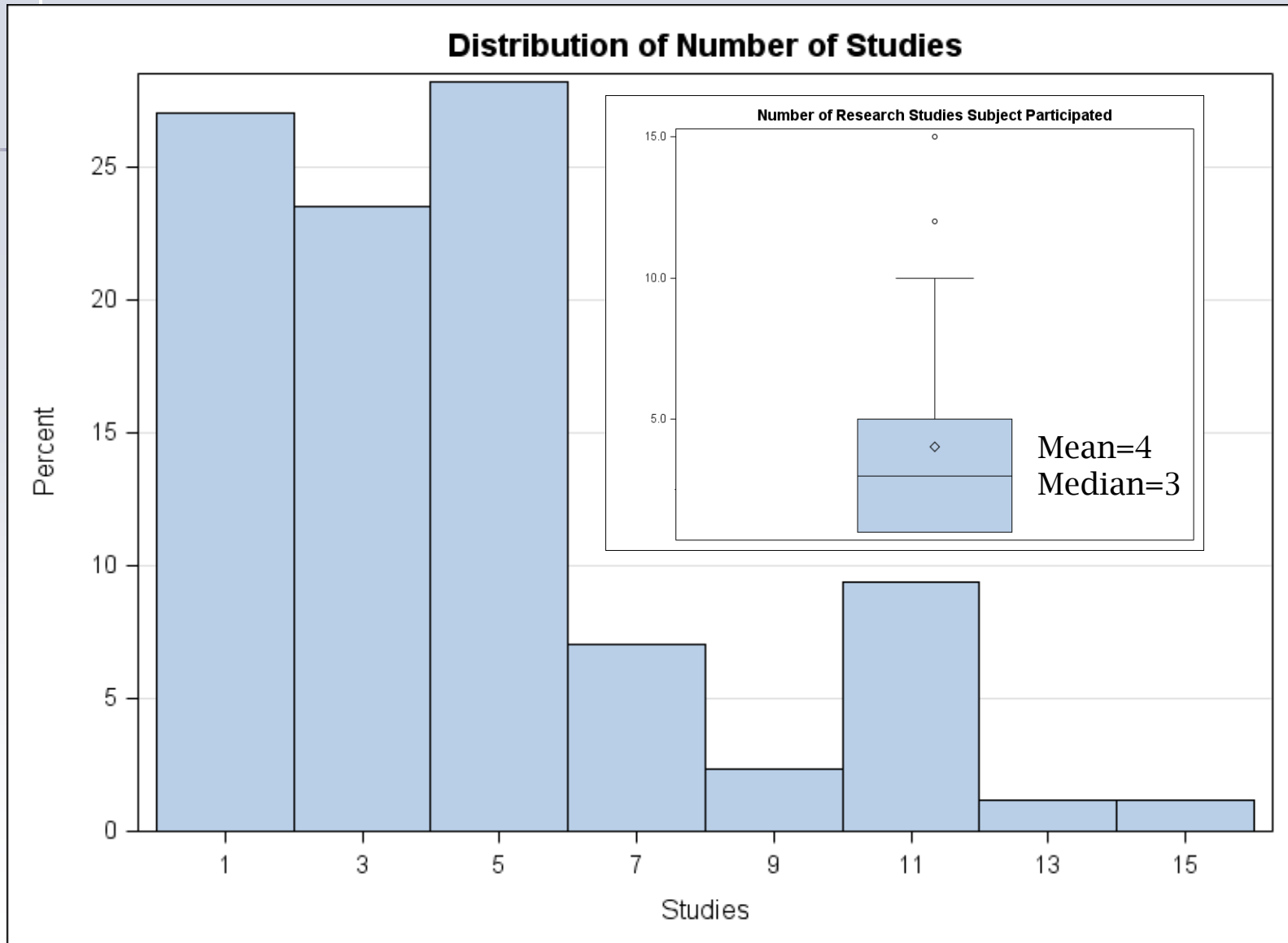
Overall Results:

Stanford Study Subjects:

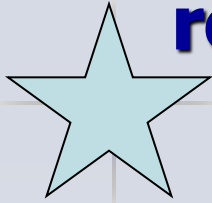
- satisfied
- safe
- well cared for
- experience was worthwhile



Stanford Research "Repeat Offenders"



How satisfied subject was with research experience correlated with repeated research participation



Factors that Correlated the Strongest with Level of Satisfaction with Research Experience



- Time to consider participation
- No pressure felt during enrollment
- Adequately compensated
- Center fosters research awareness and participation
- Working with research coordinators as an incentive

All Spearman's $\rho > 0.4$
 $p < 0.001$

Factors also correlated with level of satisfaction but less strongly



- Well cared for
- Worthwhile experience
- Adequately informed
- Questions addressed
- Thank you letter
- Studies were available quickly
- Visits accommodating
- Time well utilized
- Knowledgeable RC's

Areas for Improvement

- Adequate compensation
 - Education of patients/families.
- Clinic staff to foster research participation
 - Continuing education of clinic staff.
- Studies to open for enrollment in a timely manner
 - Continue efforts to streamline contract/budget process.
- Some recruitment strategies found not helpful
 - Develop new recruitment strategies.

Acknowledgements:



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