# THERE IS NO HEALTH WITHOUT MENTAL HEALTH!

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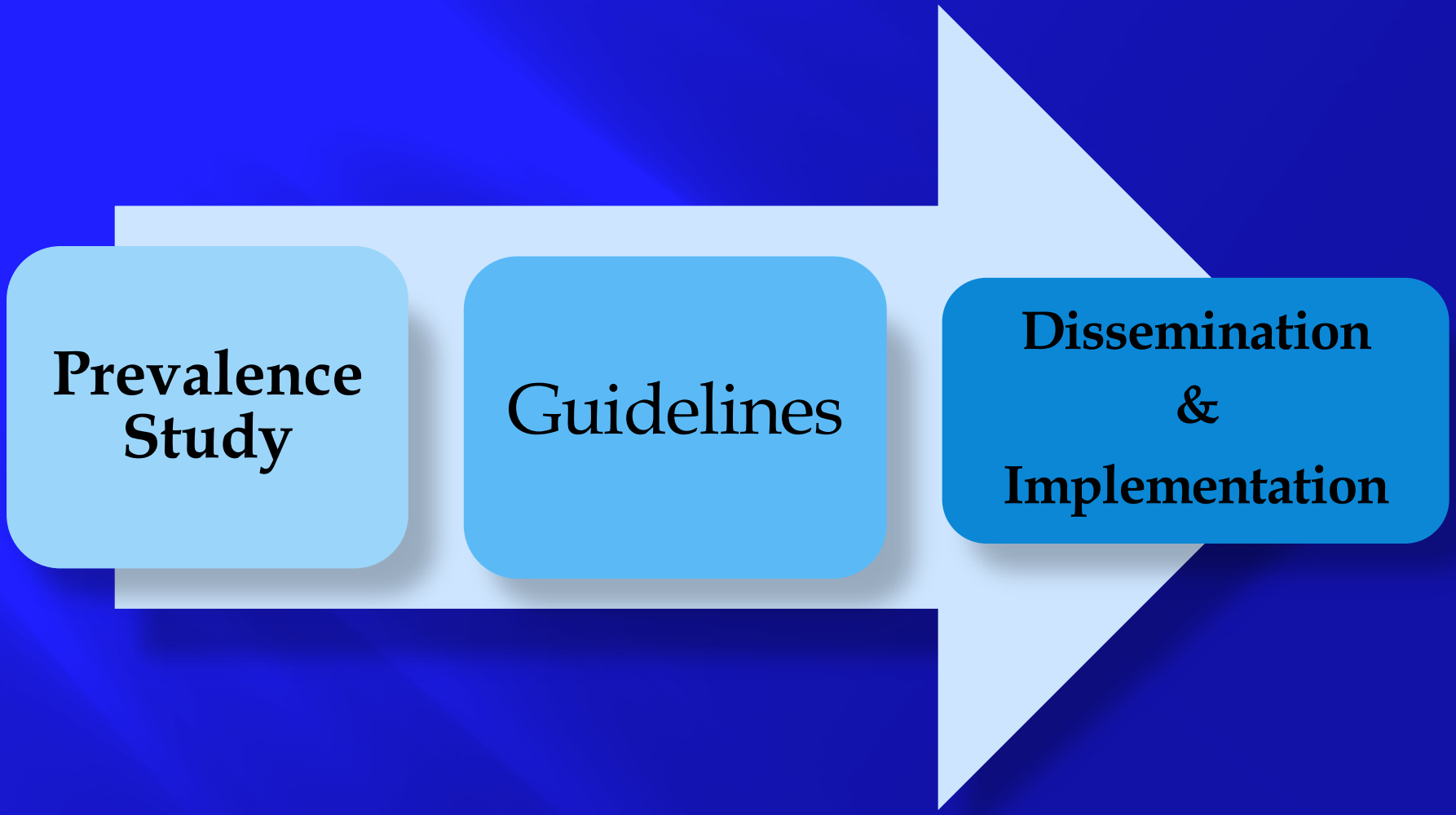
**Miami, FL USA**

# Mental Health Challenges Affect Everyone

- Rates of depression and suicide are increasing in the US among those ages 18 to 35
- Among top 10 causes of death (45,000 in 2016; CDC)
  - 2nd highest cause of death among adolescents, young adults in US
  - Has increased 70% among adolescent girls
- Increasing rates in Australia too (over 1/3 of deaths in 2016 among those 15-24 years; AnglicareSA)
- Physicians have highest suicide rate (double the community rate; 1 physician each day)

# International Dissemination & Implementation



# The Family System

Parent-Child Relationship

Marital Relationship

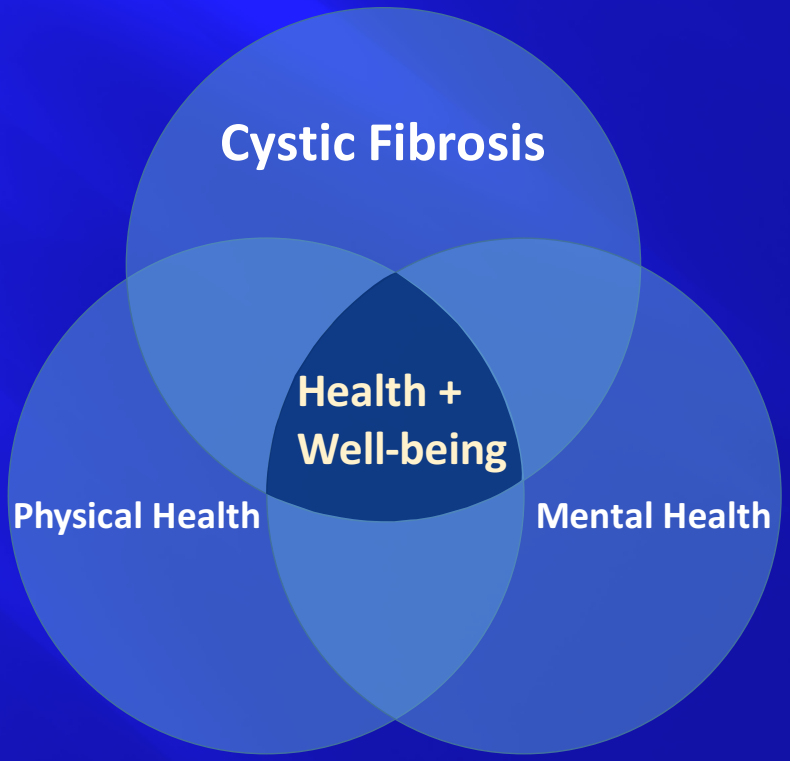
Sibling Relationship

Individuals

# Framework for Mental Health

***1st Premise:*** **Our well-being includes *both* physical and mental health**

## Treating the Whole Person



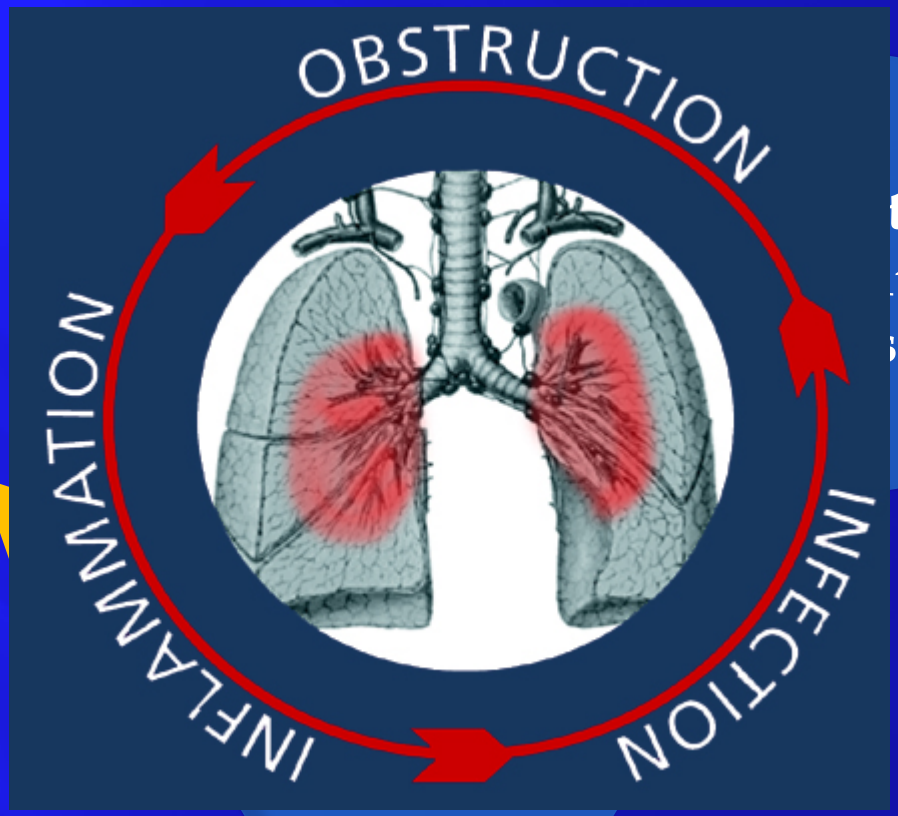
# Our Premises

**$2^{nd}$ *Premise:* We have reliable, valid tools to measure these symptoms**

**$3^{rd}$ *Premise:* If you have a chronic illness, or if you care for a child with a chronic illness**

- **Feelings of depression and anxiety are *normal* responses to a challenging situation**
- **Importantly, these feelings affect our behavior**

# Impacts of Cystic Fibrosis

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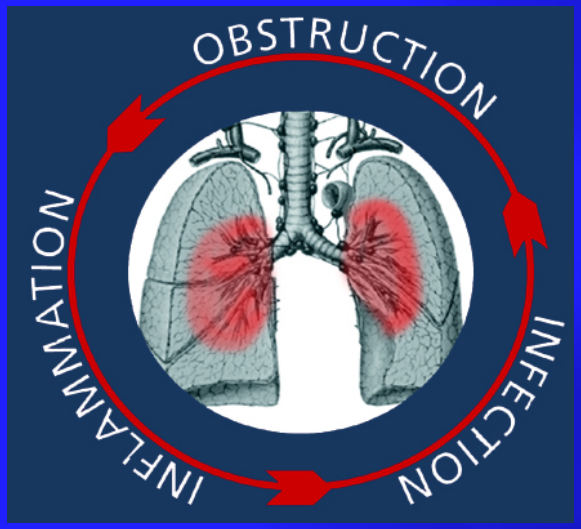
# Impacts of Cystic Fibrosis




**Mental Health (Depression)**

- **Clinic Attendance**
- **Exacerbations**
- ***Adherence***
- ***Mortality***
- **Quality of Life**

# Chronic Conditions & Mental Health

- Individuals with chronic conditions are at greater risk for symptoms of depression and anxiety[1,2]
  - Parent caregivers are also at elevated risk[3]
- In CF, single center studies have also found elevated rates of depression and anxiety[4-6]
- So the international community decided to assess the prevalence of these symptoms…

In our patients & parents
in 9 countries

# Parent Video

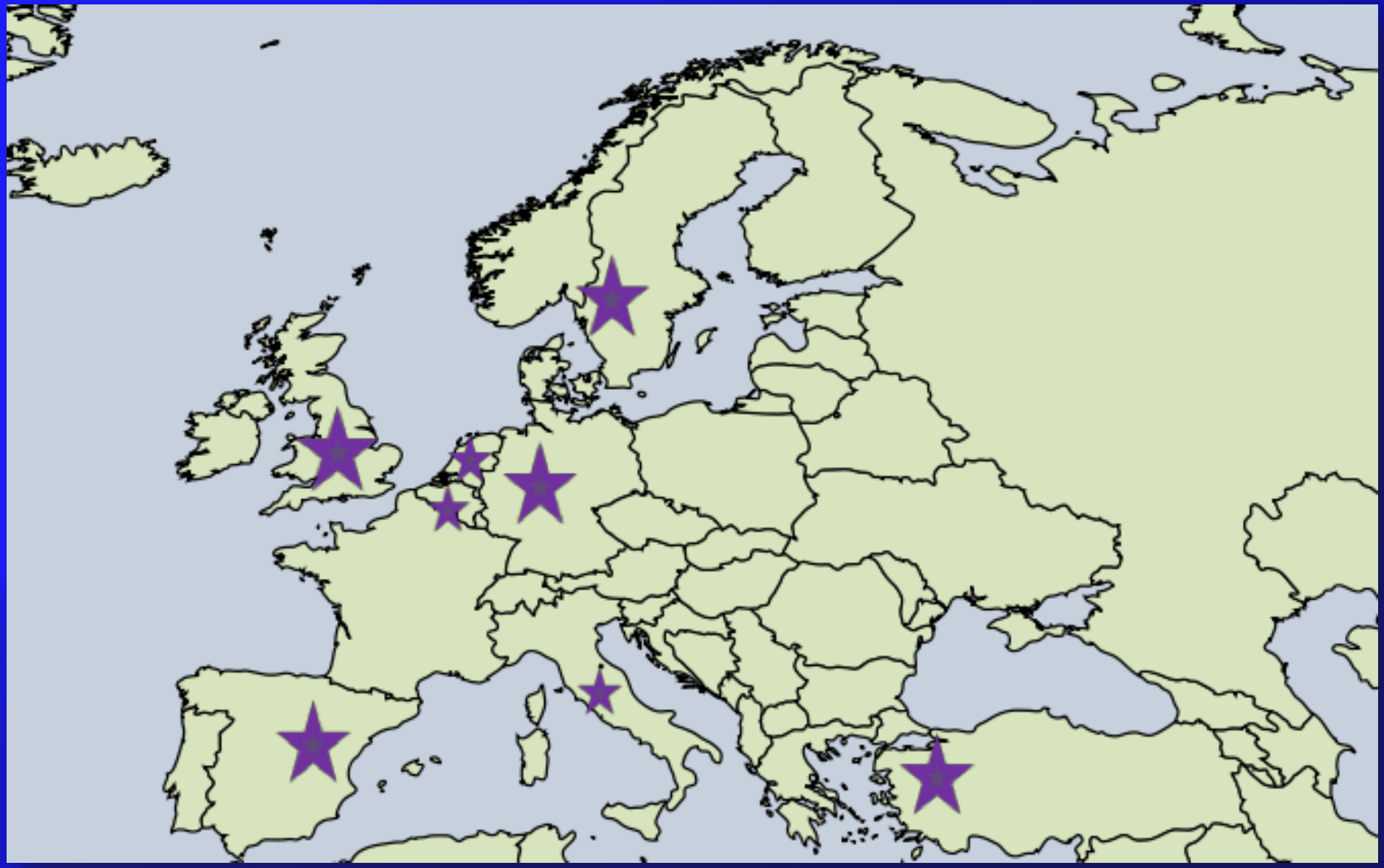
# THE INTERNATIONAL DEPRESSION/ANXIETY EPIDEMIOLOGICAL STUDY (TIDES)

*Funded by CF Foundations in Several Countries*

Quittner et al (2014), *Thorax*

TIDES
The International
Depression /Anxiety
Epidemiolgical Study

# 8 Participating European Countries



# Participating Centers in US
# N = 45 CF Centers

# Methods

- ***We screened 6088 patients & 4102 parent caregivers!!***

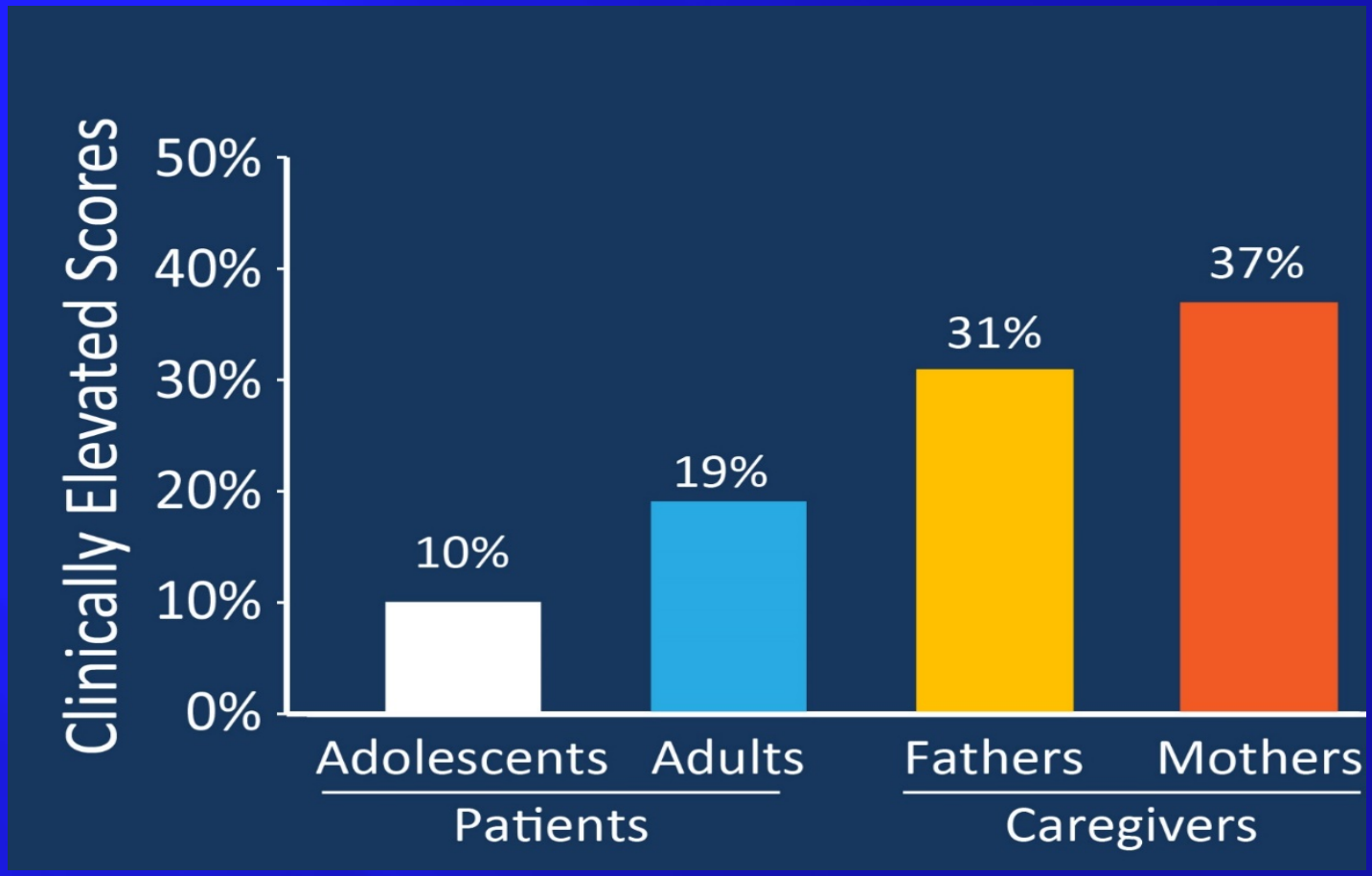
- **Two brief screening measures of depression & anxiety (5 minutes each) administered in clinic by CF Team member (i.e., social worker, nurse, psychologist)**
  - **Hospital Anxiety Depression Scale (HADS)**
    - **Depression = 7 items**
    - **Anxiety = 7 items**
  - **Center for Epidemiological Studies-Depression (CES-D)**
- **Background/medical information form, verified by chart review**

# Participant Characteristics by Respondent

| Respondent | | | | |
|---|---|---|---|---|
| | Adolescents | Adults | Mothers[a] | Fathers[a] |
| Sample size | 1272 | 4701 | 3026 | 954 |
| Age, mean (SD), years | 14.99 (1.58) | 28.85 (9.52) | 8.91 (5.06) | 8.51 (5.16) |
| Female, % | 659 (53%) | 2251 (49%) | 1538 (51%) | 455 (48%) |
| BMI, mean (SD) | 19.58 (2.99) | 21.87 (3.53) | 17.46 (2.97) | 17.28 (2.93) |
| $FEV_1$ % predicted, mean (SD) | 84.16 (23.58) | 62.24 (24.55) | 89.19 (21.58) | 90.48 (22.27) |

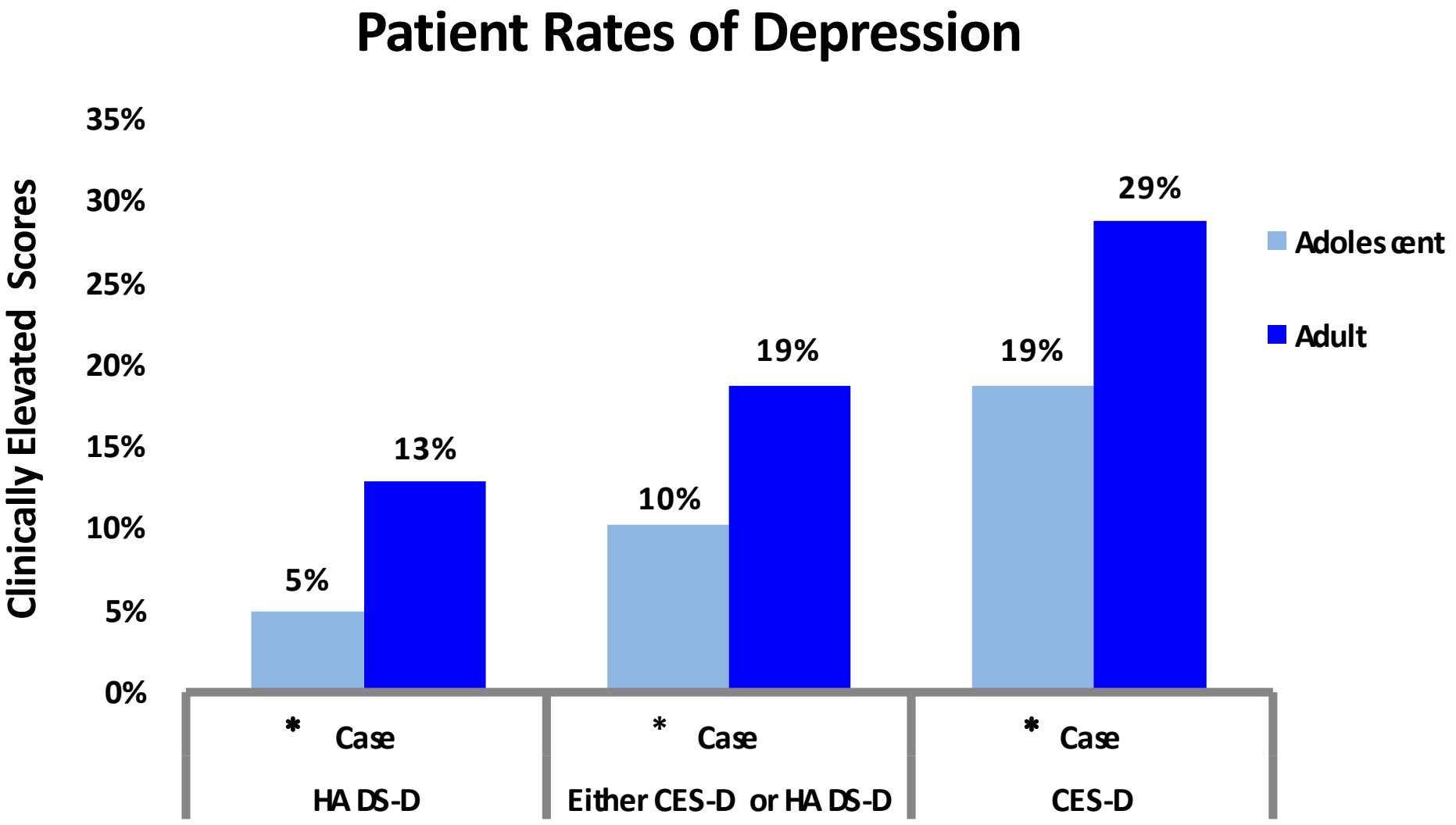
Notes: [a] *Characteristics of younger patients whose parents completed the screening*

# TIDES: Prevalence of Depression above the Clinical Cut-Off Score



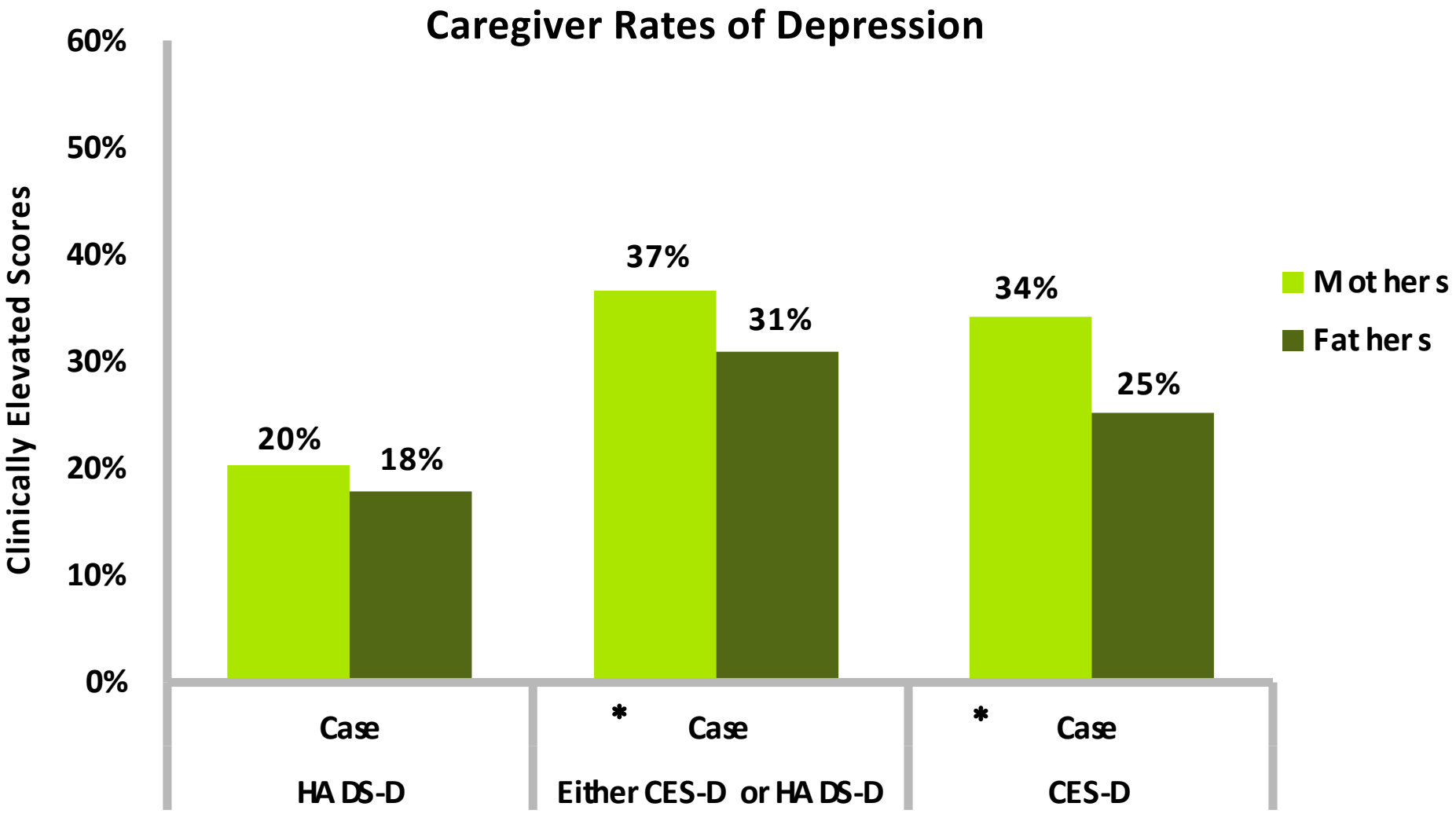

Quittner et al. Thorax. 2014;69(12):1090-7.

# Higher Prevalence in Adults




*p< .001

# Higher Prevalence in Mothers



# Concordance: Parent-Teen Depression & Anxiety

- For the 1130 parent-adolescent dyads, adolescents were *4.80 times* more likely be above the cut-off for depression if one parent was elevated*
- Similarly, adolescents were *3.53 times* more likely to be above the cut-off for anxiety if one parent was elevated
- **Elevated on either measure*

# Conclusions

- There is a high prevalence of anxiety and depression in people with CF and caregivers
  - 2-3 X prevalence in community
  - Effects on adherence, health outcomes and resource utilization are well-described
- Concordance between parent-teen symptoms suggest that we need to screen both patients and caregivers
- *Analysis of mortality over 5 years-depression*
- Quittner et al., Thorax (2014)

# DEPRESSION & ADHERENCE

# ONE DAY'S TREATMENT!

# Studies Linking Depression & Adherence

- Study 1: Do depression and anxiety affect mortality?
- Study 2: Does depression in mothers affect enzyme adherence?

# Study 1: Depression & Anxiety in US TIDES Data

- We followed almost 1,000 adults who were screened for depression and anxiety in the TIDES study
- We followed them for 5 years, tracking their health outcomes in the CFF Registry
  - Depression, but *not* anxiety, was related to death in 5 years
  - Adults who were depressed were 2X more likely to die within 5 years than those who did not screen positive

- Schechter et al., under review

# The Family System

Parent-Child Relationship

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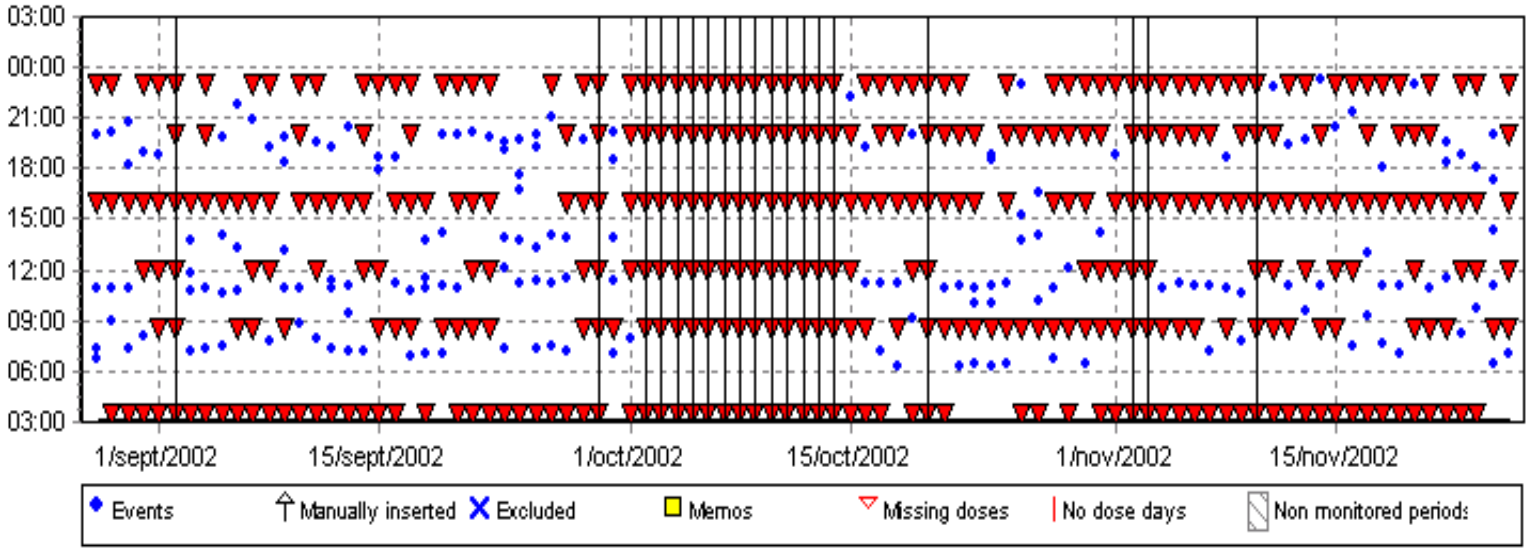
# Study 2: Adherence to Enzymes

## ENZYME MONITOR (MEMS CAP)



# Enzyme Adherence & Maternal Depression

## 3 CF Centers (88 Families)

### Caregivers

| | |
|---|---|
| Mothers | 82% |
| Income | $48,248 |
| Medicaid | 39% |
| Education | 14 years |
| # of children | 2.04 |

### Child

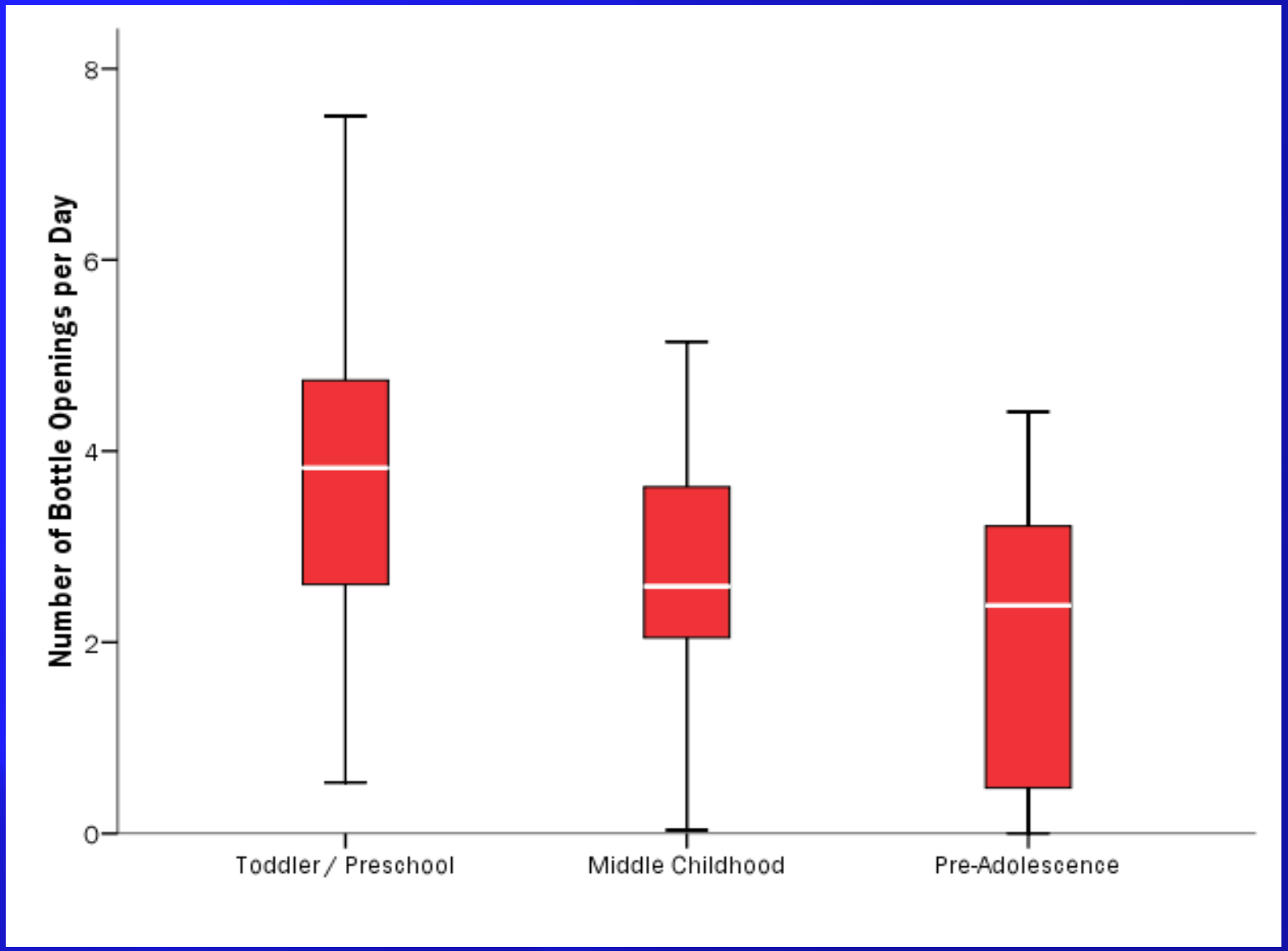
| | |
|---|---|
| Age | 6 years 4 months |
| $FEV_1$ % predicted | 87.63 |
| Weight Percentile | 39.96% |
| Height Percentile | 33.97% |
| BMI Percentile | 51.32% |

Barker & Quittner, 2016, *Pediatrics*

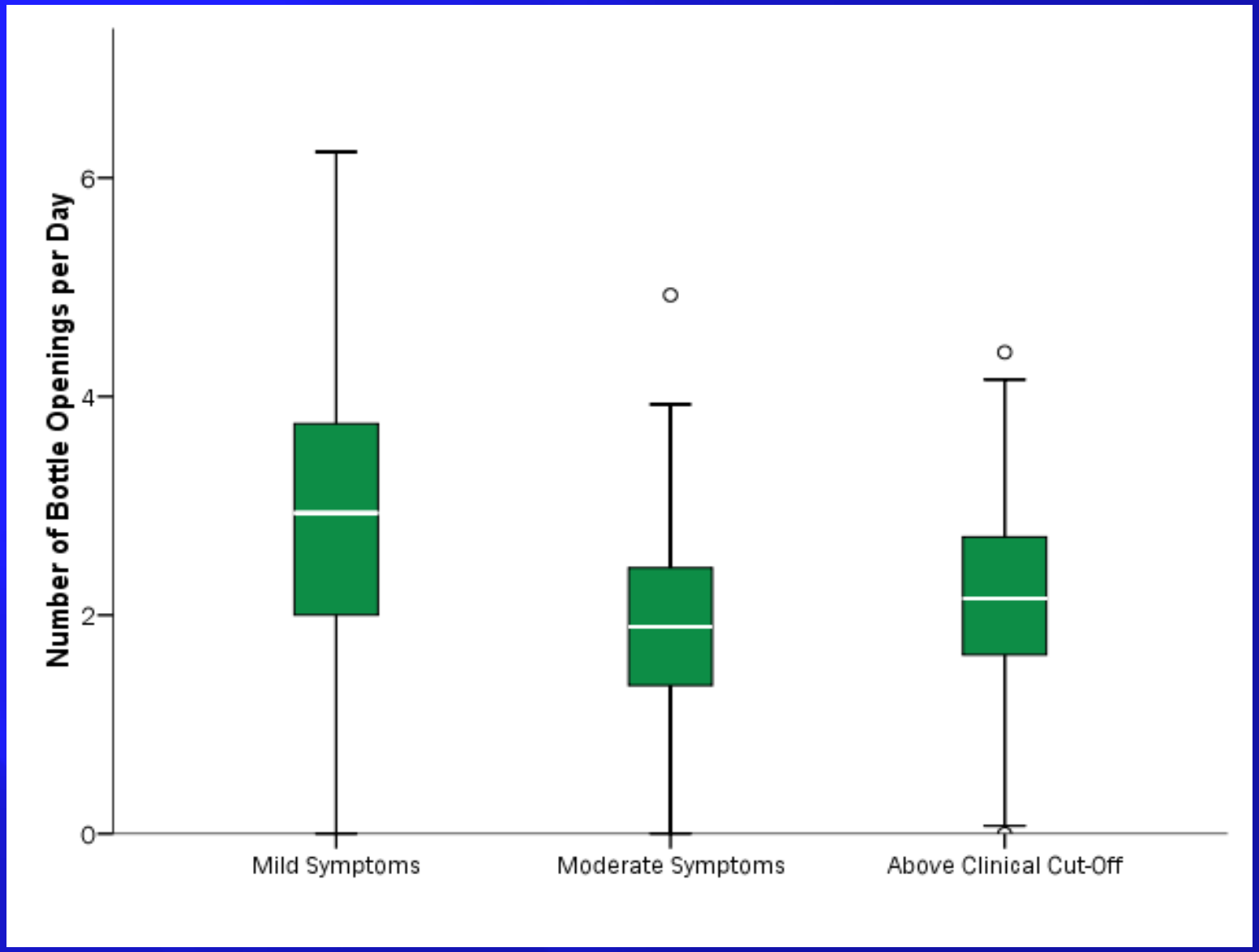
# Depression & Adherence

- Caregiver depression
  - 30% scored above cut-off score on the CES-D
- Adherence to enzymes
  - CF Foundation guidelines = 3 meals & 3 snacks
  - 46% adherent at *home* (2.8 bottle openings/day)
  - 86% adherent at *school* (.86 bottle openings/day)

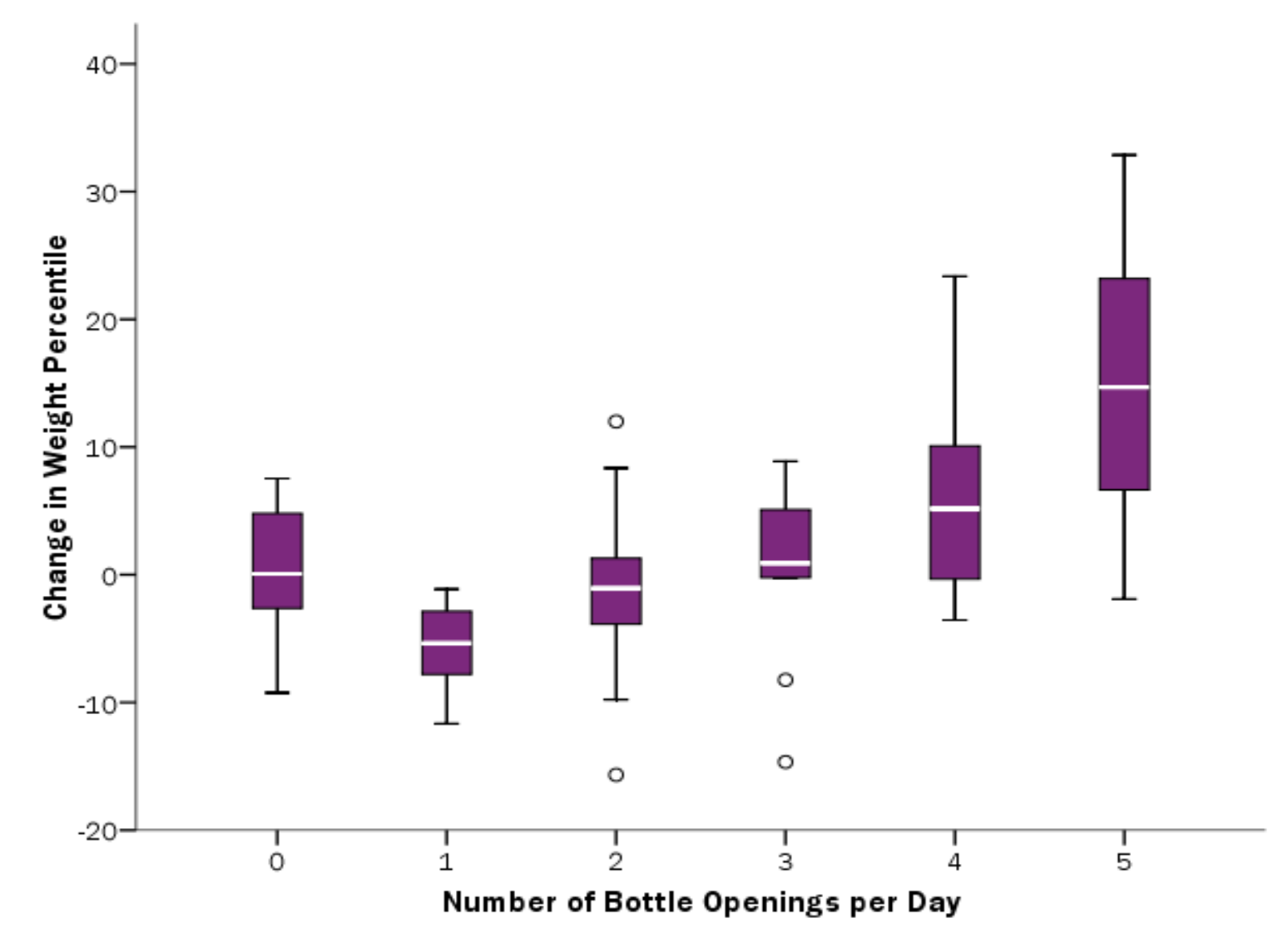
# Age & Enzyme Adherence



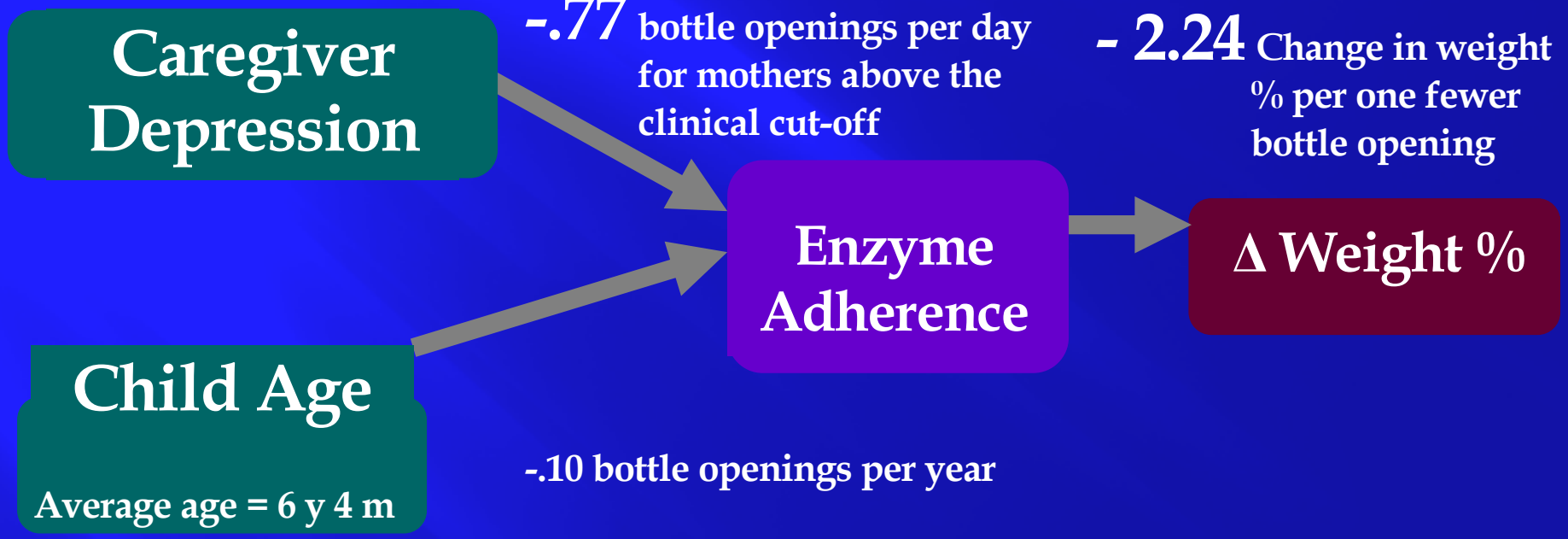
# Depression & Enzyme Adherence



# Enzyme Adherence & Weight Gain



# Depression, Enzyme Adherence & Weight Gain



# Conclusions

- 1st Study to measure adherence to enzymes electronically (prior studies used self-report)
- 1st study to link caregiver depression to adherence in CF
- 1st study to establish a short-term link between adherence to enzymes & changes in weight over 3 months

Barker & Quittner, 2016, *Pediatrics*

# How does caregiving affect parents?

- Marital role strain (Quittner AL, et al. *Health Psych*.1998; 17:112-124)
- Differential treatment of siblings (Quittner AL, et al. *Child Devel*. 1994; 65:800-814)
- Depression
- Anxiety

*Parental distress linked to child outcomes, so we need to support parents*

# The Family System

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# Role Strain in Couples: Effects on Marital Satisfaction

66 Couples with a child ages 2-6

33 couples-child with CF

33 matched couples-child without CF

- Division of household & child-care tasks
- Parenting stress, marital satisfaction, intimacy, and depression
- Daily phone diaries over 24 hours

Quittner, A.L. et al., (1998), Health Psychology, 17, 112-124.

# Role Strain in Couples

- Couples in CF group compared with comparison group:
  - Higher levels of conflict over child rearing
  - More frustration in their roles & division of parenting tasks
  - Fewer positive daily interactions
- Wives in CF group reported highest levels of parenting stress
- Husbands reported lower parenting stress

# Recreation Time

| | Cystic Fibrosis Group | | Comparison Group | |
|---|---|---|---|---|
| | Wives | Husbands | Wives | Husbands |
| | *M* (SD) | *M* (SD) | *M* (SD) | *M* (SD) |
| # of in-home activities | 3.17 (1.90) | 3.15 (1.47) | 4.07 (1.37) | 4.02 (1.36) |
| # of out-of-home activities | 1.75 (0.97) | 1.45 (0.69) | 2.24 (1.10) | 1.75 (0.89) |

***Couples in CF group vs. comparison group reported fewer recreational activities***

# Coping Strategies: Share Caregiving Responsibilities

- How can couples support one another?
  - Share caregiving and parenting tasks
  - Dads need to be more involved and take on more responsibility!
  - Moms must be willing to "let go" (less perfect!)

# The Family System

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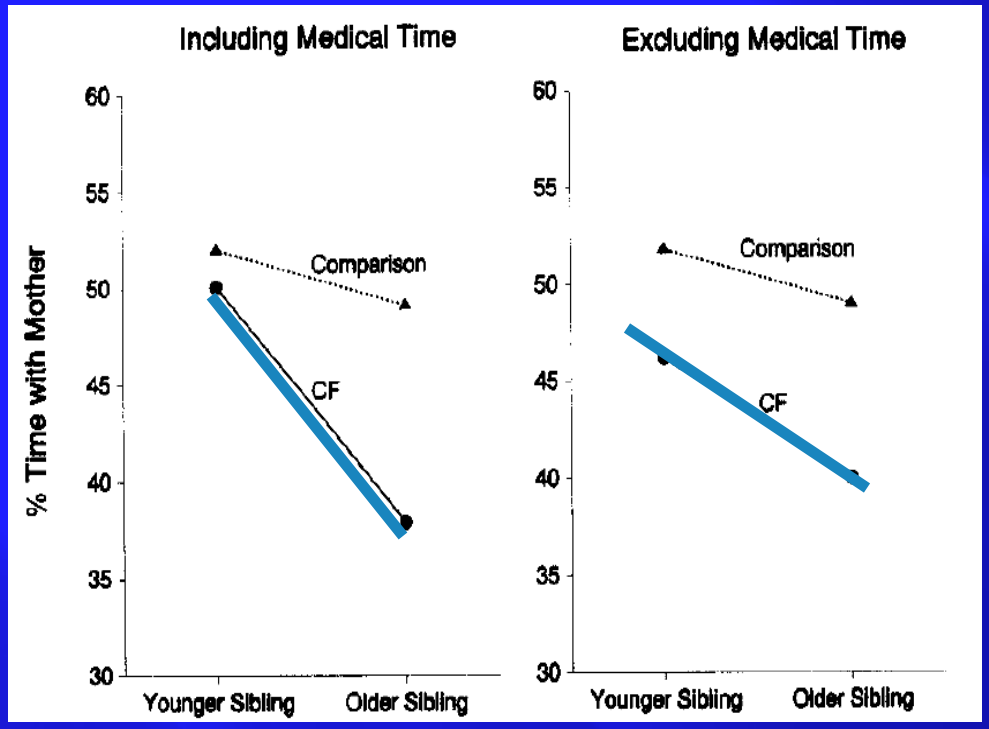
# Parent Differential Treatment (PTD)

- 2 groups of families:
  1. Younger child had CF and older child was healthy (N = 20)
  2. Both children were healthy (N = 20)
- 3 types of data collected:
  1. Home interviews
  2. Nightly phone interviews
  3. Daily diaries

Quittner, A.L. & Opipari, L.C. (1994). Differential treatment of siblings: Interview and diary analyses comparing two family contexts, *Child Development*, 65, 800-814.

# Differential Treatment

## Total Time with Siblings, with and without Medical Care




## Total Time with Siblings, with and without Medical Care

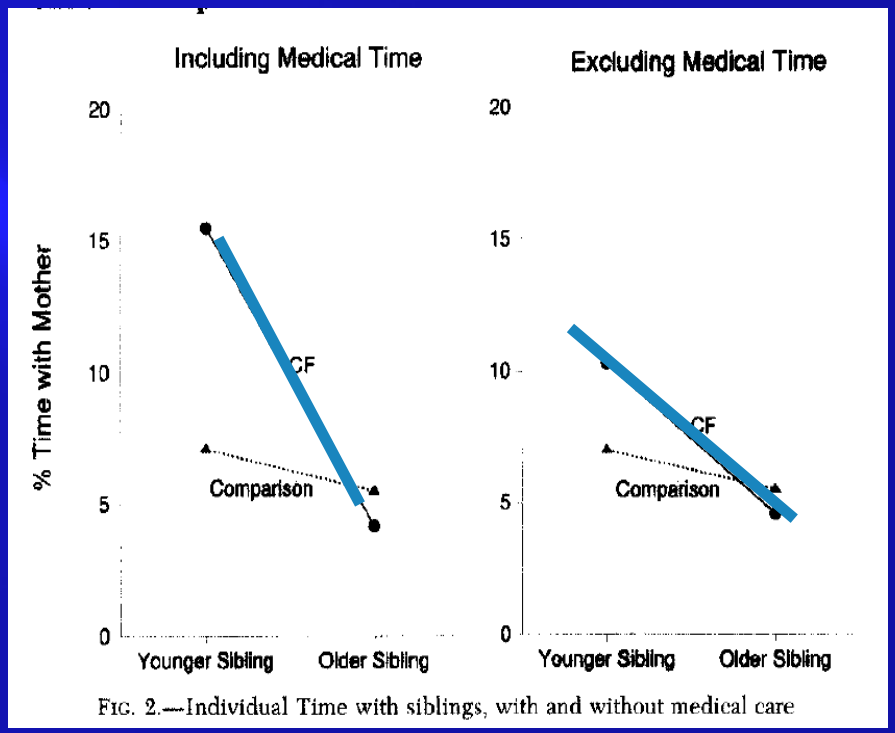



FIG. 2.—Individual Time with siblings, with and without medical care

Quittner, A.L. & Opipari, L.C. (1994). Differential treatment of siblings: Interview and diary analyses comparing two family contexts, *Child Development*, 65, 800-814.

# Group Differences in Time Spent in Activities

TABLE 1

DEFINITIONS OF ACTIVITIES AND DIFFERENCES BETWEEN SIBLINGS IN PROPORTIONS OF TIME IN ACTIVITIES

| Activity Definitions | CF Group | Comparison Group | $F$[a] |
|---|---|---|---|
| *Household Tasks:* Caring for the house or yard (e.g., cleaning, laundry, grocery shopping, mowing lawn) | 15.2 (38.8) | 12.5 (31.8) | .06 |
| *Mealtimes:* Preparing and consuming food (e.g., making dinner, eating breakfast, going to a restaurant) | 11.7 (12.7) | 4.8 (8.3) | 4.20* |
| *Child Care:* Meeting basic physical needs of the child (e.g., dressing, bathing, changing diapers) and facilitating child's play (e.g., getting out toys, taking to class) | 9.7 (22.9) | 8.0 (20.4) | .06 |
| *Playtime:* Playing with or nurturing the child (e.g., coloring, reading, bike riding, cuddling) | 34.2 (46.7) | 9.1 (25.1) | 4.49* |
| *Medical Care:* Caring for child's health. Includes daily CF regimen (e.g., enzymes, antibiotics, chest physiotherapy) as well as health care concerns not related to CF (e.g., doctor visits) | 77.9 (25.5) | 1.8 (27.1) | 83.48** |

NOTE:—Standard deviations are in parentheses.
[a] Based on univariate ANOVAs.
* $p < .05$.
** $p < .001$.

# Coping Strategies for Siblings

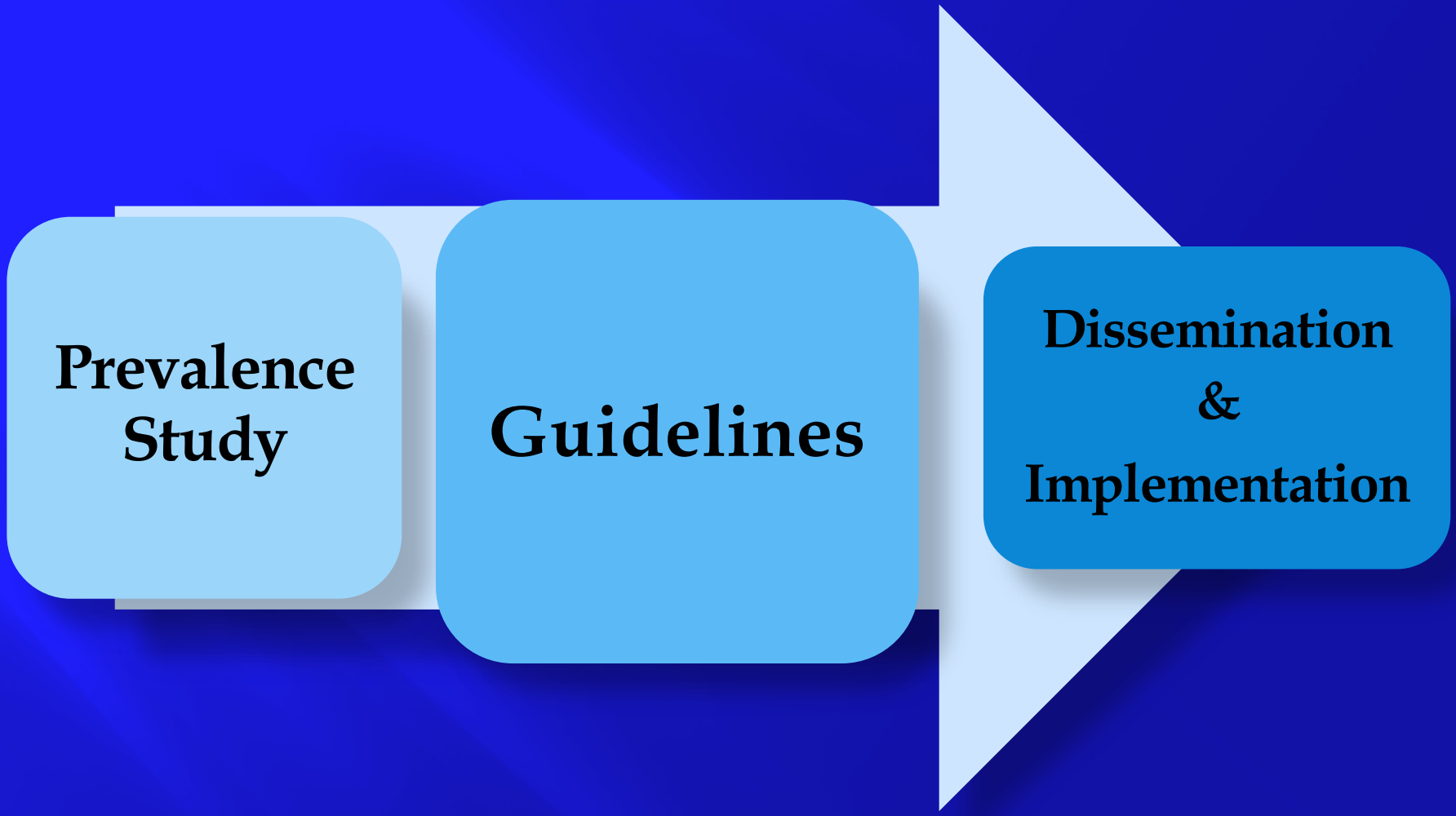
- **Important to spend "special time" with healthy sibling, especially when child with CF is sick or in hospital**
- **Provide extra support to siblings (stay with grandparents, everyone gets presents)**
- **Avoid making older child a "caregiver"**
- **Shift focus away from CF in the family; spend lots of time in play!**

# Message to Parents: Caregiving is Very Difficult

Feelings of depression & anxiety are *normal* responses to difficult situation

# SO WHAT DO WE DO ABOUT DEPRESSION & ANXIETY?

# International Dissemination & Implementation



# INTERNATIONAL GUIDELINES ON MENTAL HEALTH IN CF

**Alexandra L. Quittner & Stuart Elborn, Chairs**

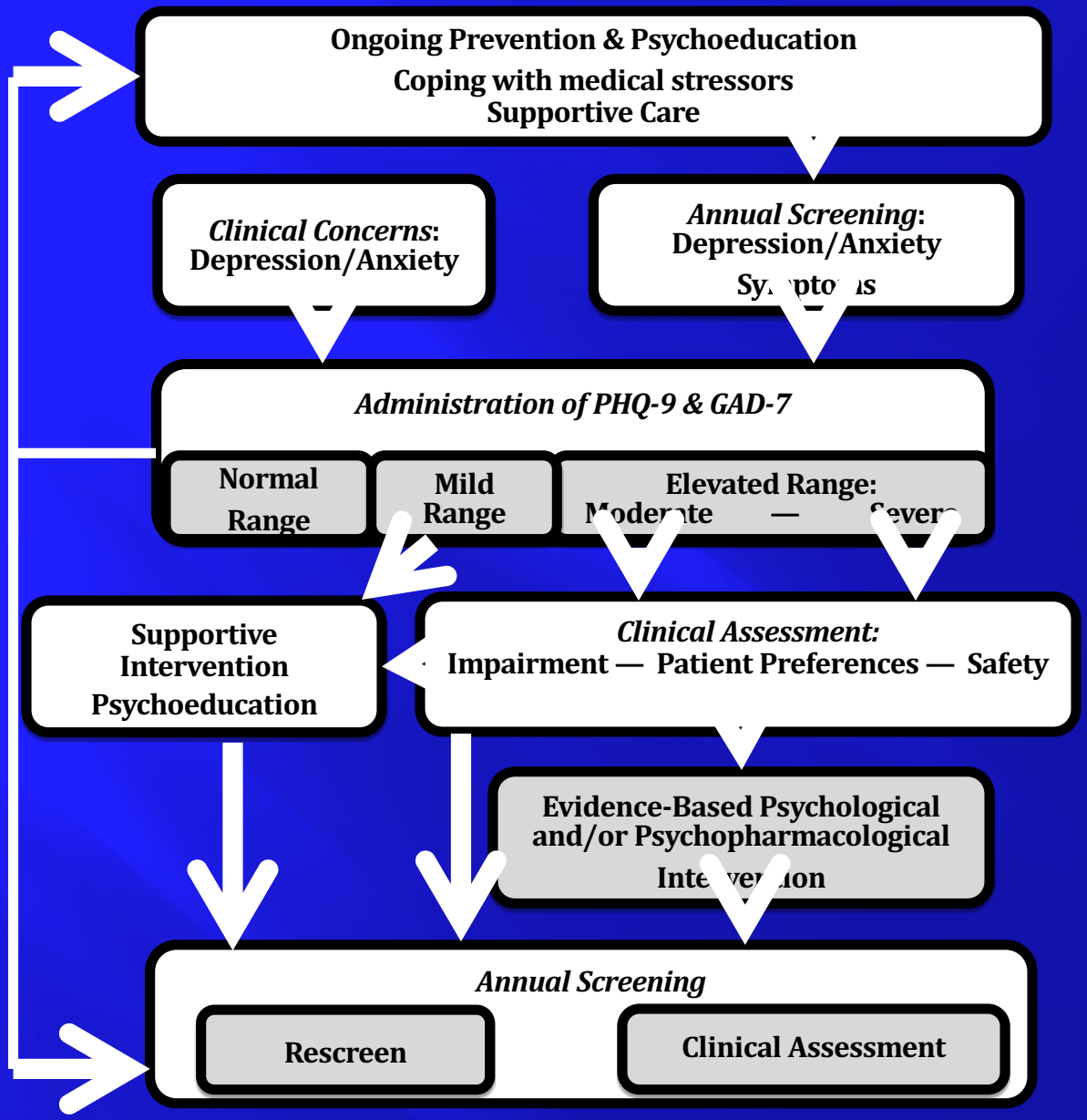
**Quittner et al., *Thorax* (2016)**

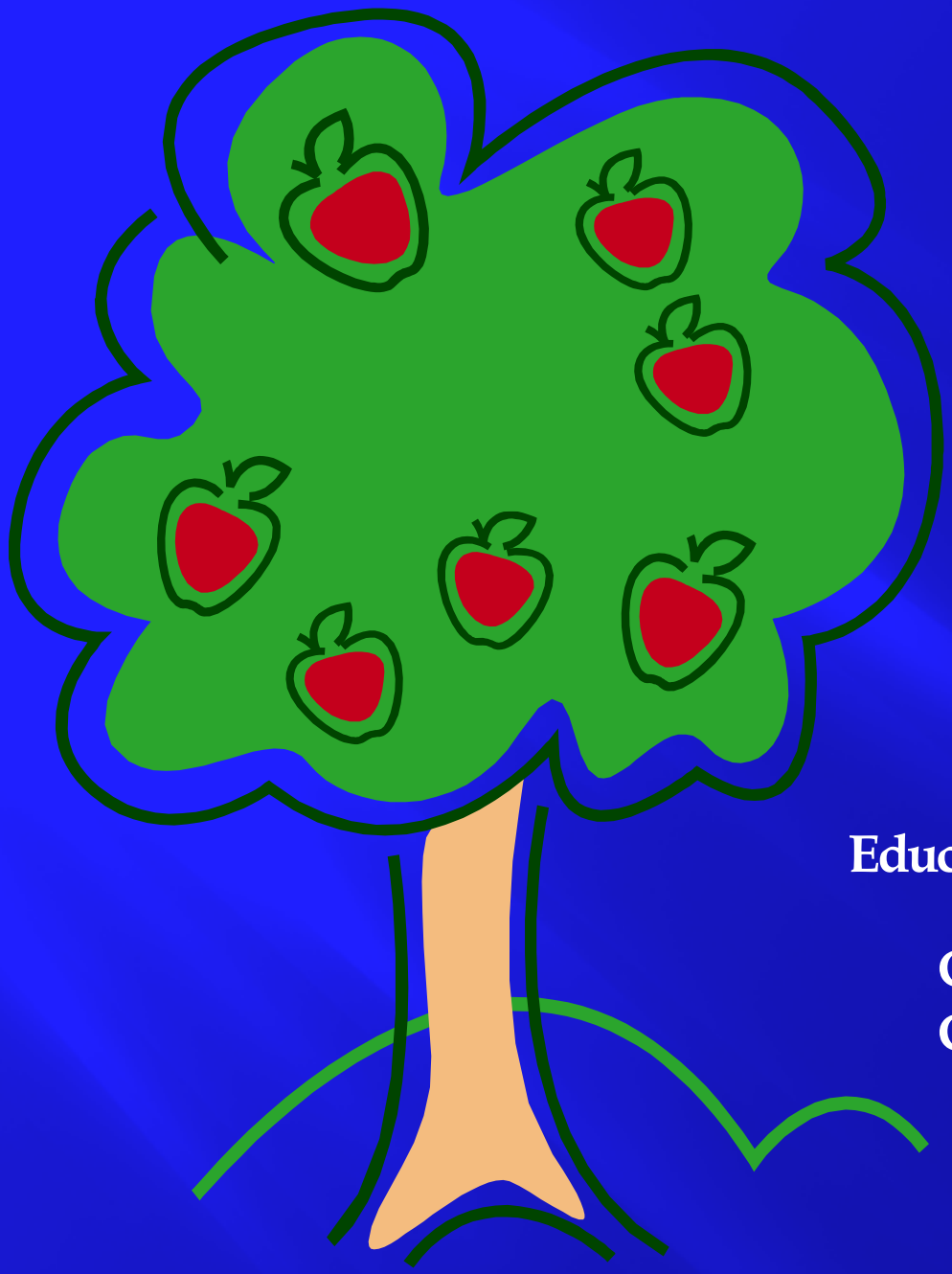
# International Guidelines Committee

- Sponsored by CFF and ECFS
- Health care providers and researchers from Europe & US:
  - Pulmonologists, psychologists, psychiatrists, pharmacists, health services researchers, nurses, social workers
  - Adult with CF; parent of adolescent with CF
- 2-year effort to review the literature, identify *best screening tools*
- Each group formed recommendations, which were presented, discussed and voted on

# CFF-ECFS Guidelines on Mental Health in CF
# Voting on Guidelines in Italy!

# Figure 1: Assessing & Treating Depression & Anxiety in CF





# *Low Hanging Fruit*

Annual Screening: Depression & Anxiety

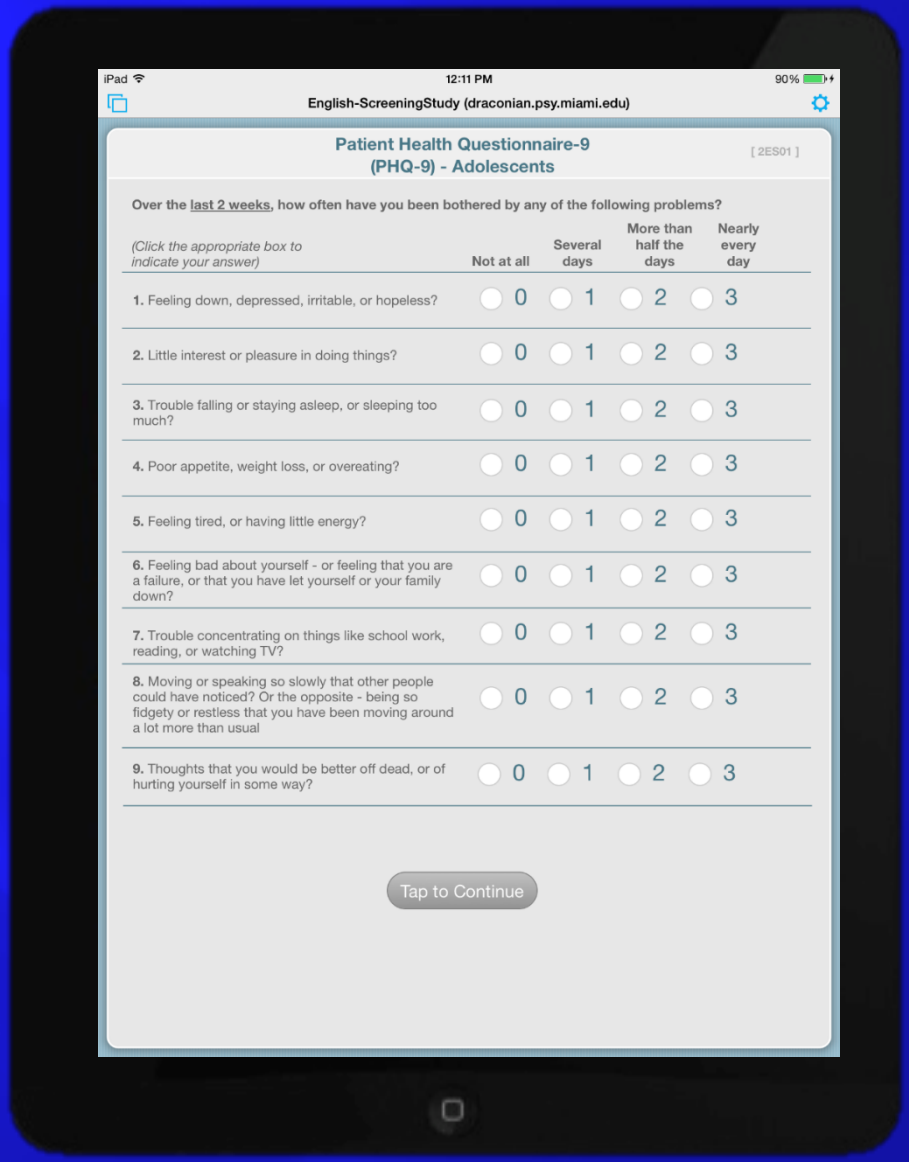
Education about Depression/Anxiety

CFF Funding for Mental Health Coordinator at 155 Centers!

Pay attention to the screening data

# Administering Screening on iPad

PHQ-9 and GAD-7 measures take 5 minutes to complete!



# Educational Materials for Staff

ABCT

A B C T F A C T S H E E T S

## DEPRESSION

*Depression is a common psychological problem, experienced by many people at some time during their lives. One member of most families has experienced an episode of depression severe enough to require formal treatment. Depressed mood is costly to individuals and society as a whole, both economically as well as in terms of quality of life.*

**Major Characteristics**

The primary feature of depression is a sad mood state, which, in its most sev
form, is experienced as a feeling of helplessness, hopelessness, and despair
When people experience depressed mood, it is common for them also to e
ence a decrease in social activities, problems with relationships, and an i
in crying or "a desire to cry even if you cannot get the tears out" (called
depression).

***Cognitive Characteristics***

There are also several cognitive features of depression that may i
concentration and memory; a belief that you are becoming wor
that things cannot be made better, have gotten bad, and will g
focus on negative things about yourself without enough atte
things about yourself.

***Biological Characteristics***

The biological characteristics of depression include dis
trouble falling sleep and a pattern of waking up very e
appetite, loss of sexual desire or lack of interest in s
tiredness during the day. It is also important to kn
pen along with increased anxiety and feelings of
of cases, depression will be followed by problem

***Frequency***

Depression severe enough to require forma
women and 3% of the men in this country
lower rates, among children. During ado
or 15 they equal those of

**What Is Cognitive Behavior Therapy?**

ior Therapy and Cognitive Behavior Therapy
treatment that are based firmly on re-
ese approaches aid people in
or goals.

ng more

ABCT

A B C T F A C T S H E E T S

## ANXIETY DISORDERS

*Anxiety is a normal emotion and common experience, and it represents one of the most basic of human emotions. At one time or another, all of us are likely to be "stressed out," worried about finances or health or the children, fearful in certain situations (such as when on a ladder or just before an operation), and concerned about what other people think. In general, anxiety serves to motivate and protect an individual from harm or unpleasant consequences.*

For many people, however, constant or excessive anxiety disrupts their daily activities and quality of life; for others, panic, which seems to come out of nowhere, can cause terrible physical symptoms, such as faintness, chills, and even extreme chest pains. Anxiety disorders are so common that more than 1 in every 10 Americans will suffer with one at some point in their lives. Fortunately, anxiety disorders can be treated, generally with short-term, effective, and cost-efficient methods.

**Types of Anxiety Disorders**

There are a number of different disorders that fall under the category of anxiety. They include Panic, Generalized Anxiety, Obsessive-Compulsive Disorder (or OCD), various Phobias (including Social Phobia and Agoraphobia), and Posttraumatic Stress Disorder (or PTSD). Each of these is described below.

*PANIC DISORDER*

On his way home from work, John is driving through hi
suddenly a child darts out into the street
brakes and swerves, just
ing furiou

**What Is Cognitive Behavior Therapy?**

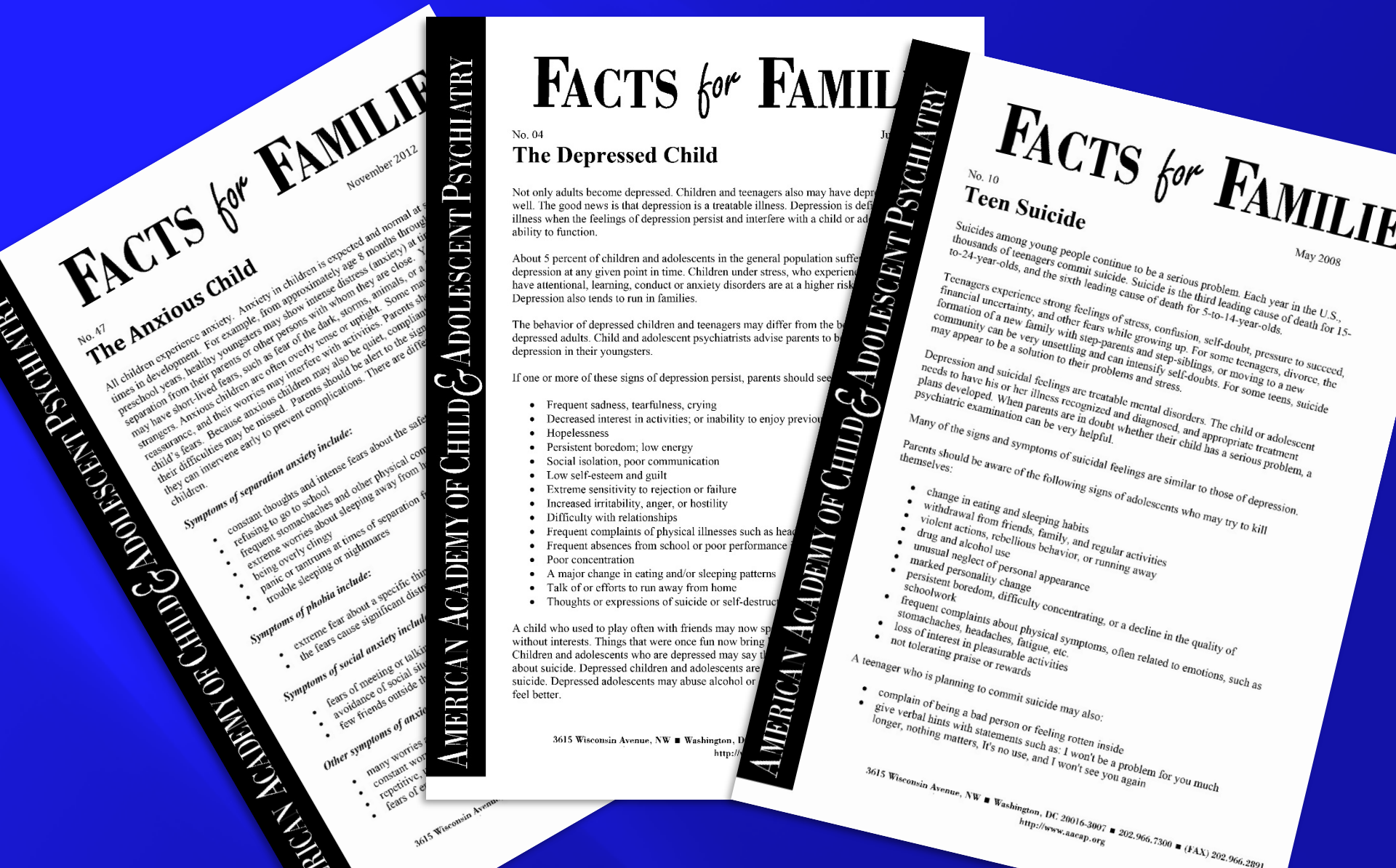
Behavior Therapy and Cognitive Behavior Therapy are types of treatment that are based firmly on research findings. These approaches aid people in achieving specific changes or goals.

Changes or goals might involve:

- A way of acting, like smoking less or being more outgoing
- A way of feeling, like helping a person to be less scared, less depressed, or less anxious;
- A way of thinking, like learning to problem-solve or get rid of self-defeating thoughts
- A way of coping, like training developmentally disabled people to care for themselves or hold a job.

Behavior Therapists and Cognitive Behavior Therapists usually focus more on the current situation and its solution, rather than the past. They concentrate on a person's views and beliefs about their life, not on personality traits. Behavior Therapists
Cognitive Behavior Therapists
ents, children, cou
of livi

# Pamphlets for Patients/Families



FACTS for FAMILIES

No. 47

November 2012

## The Anxious Child

All children experience anxiety. Anxiety in children is expected and normal at t
times in development. For example, from approximately age 8 months throug
preschool years, healthy youngsters may show intense distress (anxiety) at ti
separation from their parents or other persons with whom they are close. Y
may have short-lived fears, such as fear of the dark, storms, animals, or a
strangers. Anxious children are often overly tense or uptight. Some ma
reassurance, and their worries may interfere with activities. Parents sh
child's fears. Because anxious children may also be quiet, compliant
their difficulties may be missed. Parents should be alert to the sign
they can intervene early to prevent complications. There are diffe
children.

***Symptoms of separation anxiety include:***

- constant thoughts and intense fears about the safe
- refusing to go to school
- frequent stomachaches and other physical con
- extreme worries about sleeping away from h
- being overly clingy
- panic or tantrums at times of separation f
- trouble sleeping or nightmares

***Symptoms of phobia include:***

- extreme fear about a specific thi
- the fears cause significant distr

***Symptoms of social anxiety includ***

- fears of meeting or talki
- avoidance of social su
- few friends outside th

***Other symptoms of anxie***

- many worries
- constant wor
- repetitive,
- fears of e

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AMERICAN ACADEMY OF CHILD & ADOLESCENT PSYCHIATRY

FACTS for FAMIL

No. 04

Ju

## The Depressed Child

Not only adults become depressed. Children and teenagers also may have depr
well. The good news is that depression is a treatable illness. Depression is defi
illness when the feelings of depression persist and interfere with a child or ad
ability to function.

About 5 percent of children and adolescents in the general population suffe
depression at any given point in time. Children under stress, who experien
have attentional, learning, conduct or anxiety disorders are at a higher risk
Depression also tends to run in families.

The behavior of depressed children and teenagers may differ from the b
depressed adults. Child and adolescent psychiatrists advise parents to b
depression in their youngsters.

If one or more of these signs of depression persist, parents should see

- Frequent sadness, tearfulness, crying
- Decreased interest in activities; or inability to enjoy previou
- Hopelessness
- Persistent boredom; low energy
- Social isolation, poor communication
- Low self-esteem and guilt
- Extreme sensitivity to rejection or failure
- Increased irritability, anger, or hostility
- Difficulty with relationships
- Frequent complaints of physical illnesses such as hea
- Frequent absences from school or poor performance
- Poor concentration
- A major change in eating and/or sleeping patterns
- Talk of or efforts to run away from home
- Thoughts or expressions of suicide or self-destruc

A child who used to play often with friends may now sp
without interests. Things that were once fun now bring
Children and adolescents who are depressed may say t
about suicide. Depressed children and adolescents are
suicide. Depressed adolescents may abuse alcohol or
feel better.

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FACTS for FAMILIES

No. 10

May 2008

## Teen Suicide

Suicides among young people continue to be a serious problem. Each year in the U.S., thousands of teenagers commit suicide. Suicide is the third leading cause of death for 5-to-14-year-olds, and the sixth leading cause of death for 15-to-24-year-olds.

Teenagers experience strong feelings of stress, confusion, self-doubt, pressure to succeed, financial uncertainty, and other fears while growing up. For some teenagers, divorce, the formation of a new family with step-parents and step-siblings, or moving to a new community can be very unsettling and can intensify self-doubts. For some teens, suicide may appear to be a solution to their problems and stress.

Depression and suicidal feelings are treatable mental disorders. The child or adolescent needs to have his or her illness recognized and diagnosed, and appropriate treatment plans developed. When parents are in doubt whether their child has a serious problem, a psychiatric examination can be very helpful.

Many of the signs and symptoms of suicidal feelings are similar to those of depression. Parents should be aware of the following signs of adolescents who may try to kill themselves:

- change in eating and sleeping habits
- withdrawal from friends, family, and regular activities
- violent actions, rebellious behavior, or running away
- drug and alcohol use
- unusual neglect of personal appearance
- marked personality change
- persistent boredom, difficulty concentrating, or a decline in the quality of schoolwork
- frequent complaints about physical symptoms, often related to emotions, such as stomachaches, headaches, fatigue, etc.
- loss of interest in pleasurable activities
- not tolerating praise or rewards

A teenager who is planning to commit suicide may also:

- complain of being a bad person or feeling rotten inside
- give verbal hints with statements such as: I won't be a problem for you much longer, nothing matters, It's no use, and I won't see you again

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# High Hanging Fruit

**Prevention; painful medical procedures**

**Training new MHCs in CF**

**Training in evidence-based treatments**

**Substance Misuse**

**Sustainability!**

- **Annual Screening: Depression & Anxiety**
- **Education about Depression/Anxiety**
- **CFF Funding for Mental Health Coordinator**
- **Pay attention to the screening data**

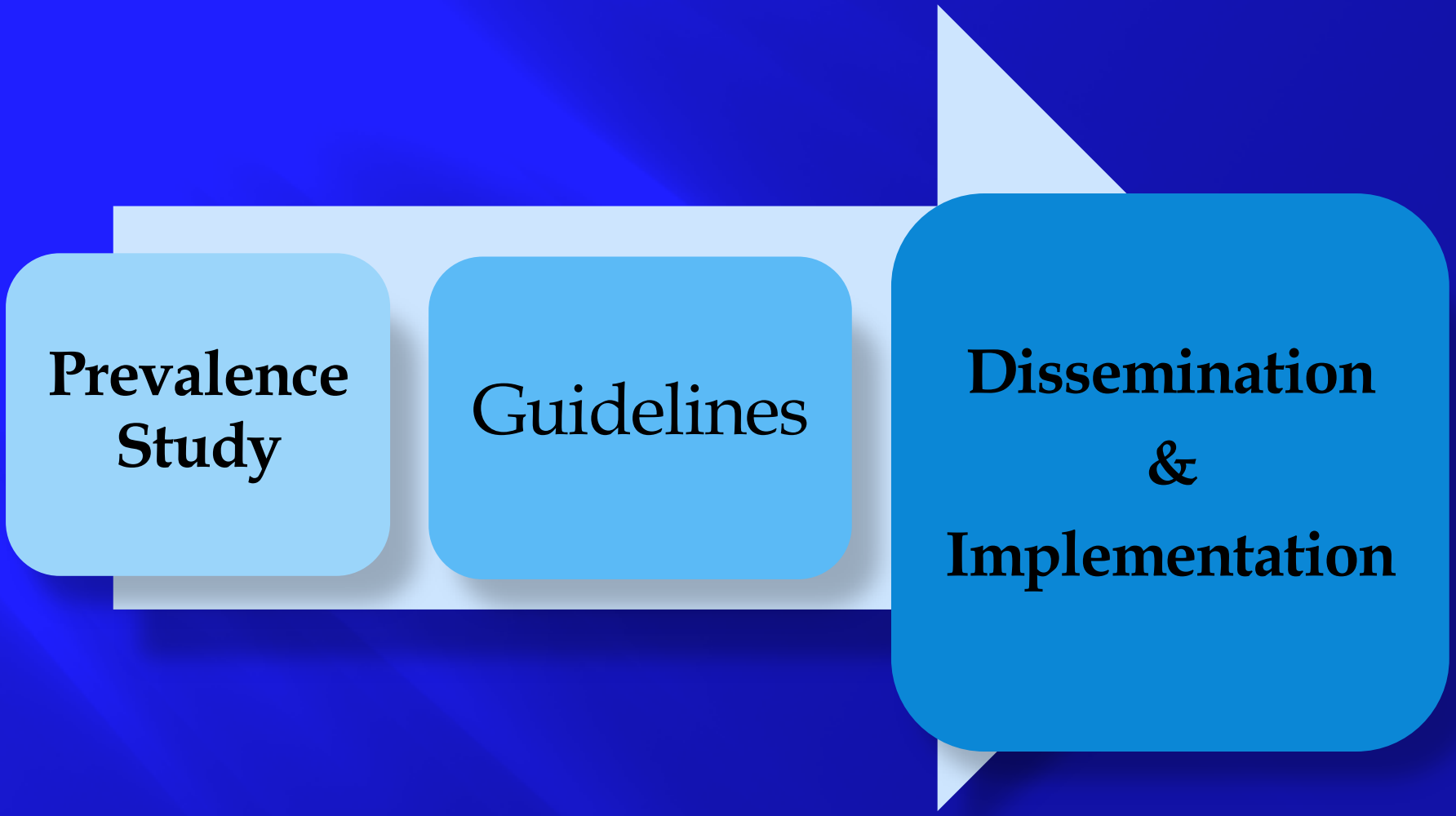
# CF Foundation Initiative on Mental Health

- **CF Foundation is implementing the new guidelines on a national scale!**
  - **138 CF Centers received 3-year funding to hire Mental Health Coordinator (social worker, psychologist) to do annual screening and provide follow-up**
  - **CFF is funding workshops, training for providers, research initiatives**
- **Annual screening of adolescents and adults with CF and parent caregivers:**
  - **Psychological support as needed**

# PRELIMINARY RESULTS OF THE DISSEMINATION & IMPLEMENTATION OF THE MENTAL HEALTH GUIDELINES IN 84 US CF CENTERS

**A. Quittner, B. Smith, T. Ong, A. Uler, S. Hempstead, P. Lomas, J. Abbott**

# International Dissemination & Implementation



# Dissemination & Implementation

- **Year 1 CFF funded 84 CF Centers**
- **Year 2 CFF, an additional 36 CF Centers**
- **We just completed Year 2 Implementation Survey on 120 CF Centers**

- ***OBJECTIVE:***
- **Results for Year 1 (50 item survey) to Mental Health Coordinators**

# Demographic Characteristics of CF Centers

| Center Characteristics (n=74); 89% response rate | |
|---|---|
| **Type of Centre n (%)** | |
| Pediatric | 29 (39.2%) |
| Adult | 22 (29.7%) |
| Pediatric & Adult | 23 (31.1%) |
| **Number of patients in Program (range)** | 13,771 (44–630) |
| **Number 12 years + (range)** | 8631 (5–492) |
| **Profession n (%)** | |
| Social Worker | 40 (54.1%) |
| Psychologist | 31 (41.9%) |
| Psychiatrist | 3 ( 4.0%) |
| **Length of time on CF team n (%)** | |
| Newly appointed | 13 (17.6%) |
| Less than 1 year | 25 (33.8%) |
| 1-5 years | 20 (27.0%) |
| More than 5 years | 16 (21.6%) |

# Screening Process

| Screening process & % of respondents | |
|---|---|
| Initiating the screening process was *somewhat easy* to *very easy* | 94.6% |
| Have begun screening with PHQ9 & GAD7 | 100% |
| Using recommended tools to screen caregivers | 44.6% |
| Using the screening tools was *somewhat easy* to *very easy* | 100% |
| Scoring the screening tools was *somewhat easy* to *very easy* | 100% |
| Interpreting the screening data was *somewhat easy* to *very easy* | 98.6% |

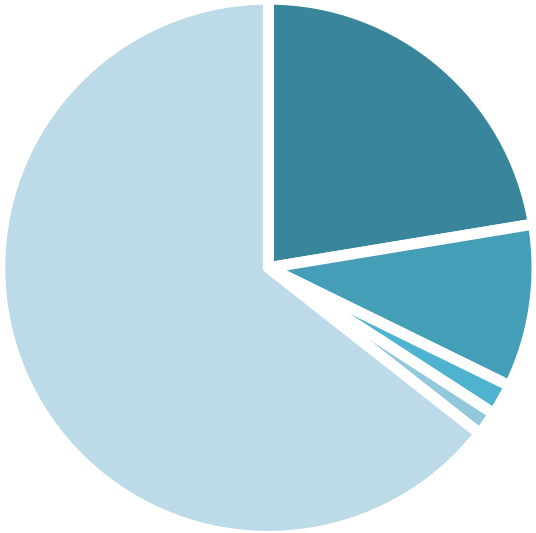
# Quantitative Results

## Patients screened for depression=5095

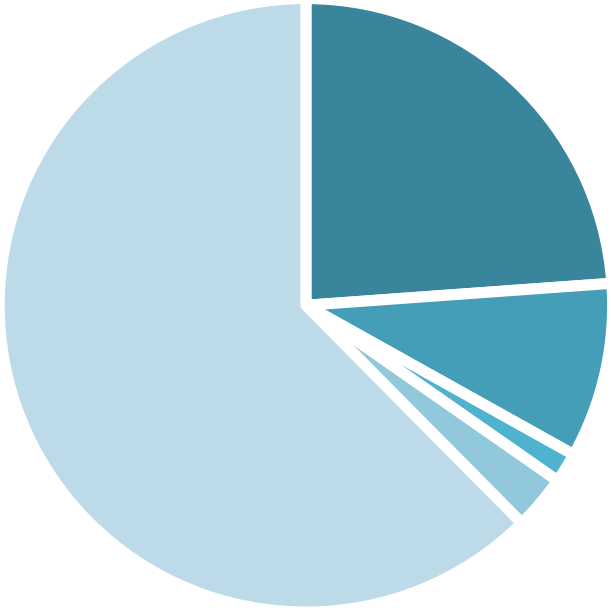
## Patients screened for anxiety n=4929

- Receiving interventions from CF Team
- Referred to outside providers
- Seen by outside providers
- Waiting for intervention
- No intervention

## *Caregivers* screened for depression n=1107



## *Caregivers* Screened for anxiety = 1006



- Receiving interventions from CF Team
- Referred to outside providers
- Seen by outside providers
- Waiting for intervention
- No intervention

# Qualitative Data: Preliminary

***Major successes in first year:***

- **increased awareness, increased identification, increased standardization**
- **reduced stigma, normalization of feelings**

***Barriers:***

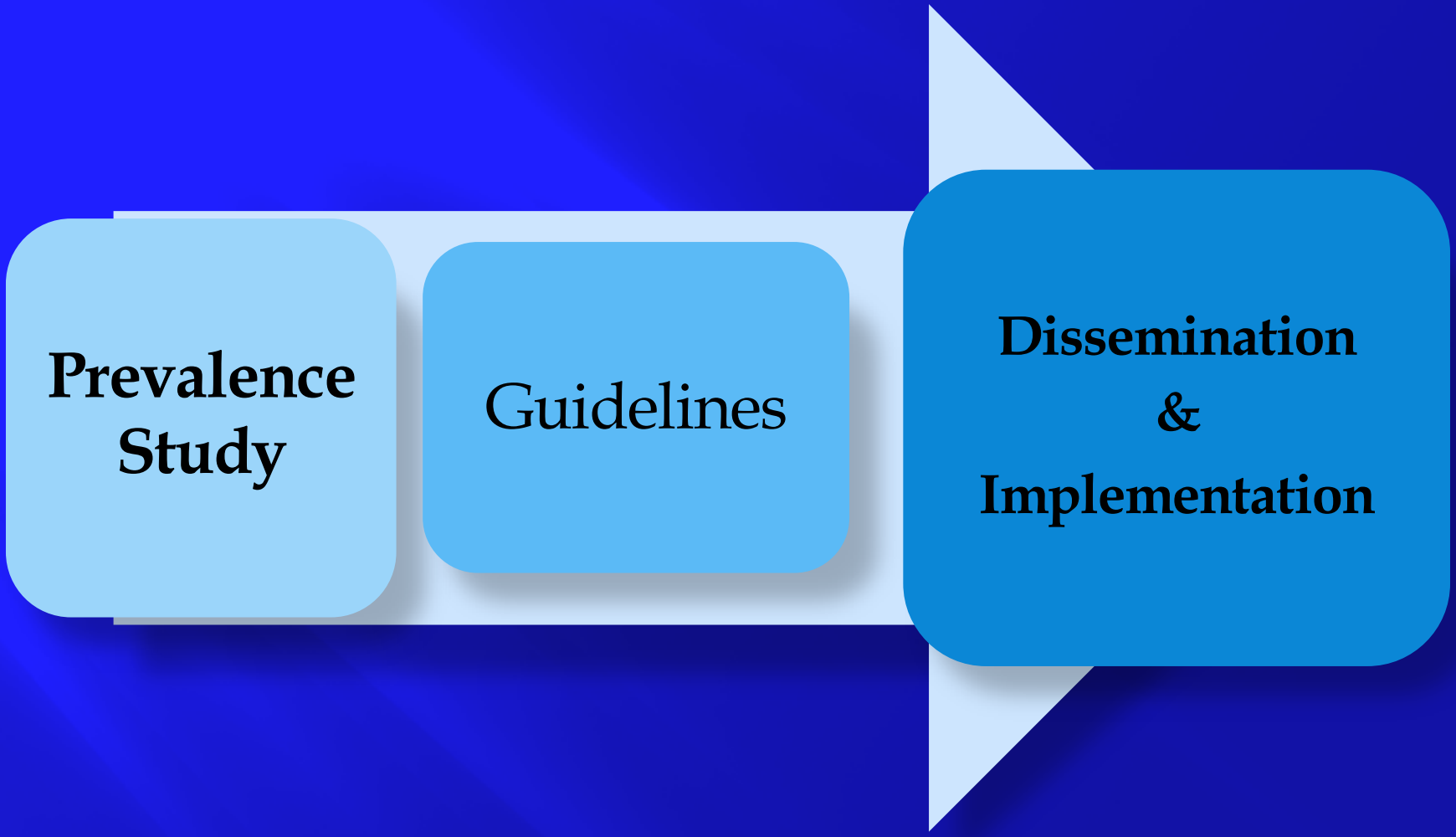
- **logistics, space**

***Training Needs & Wishes:***

**CBT, prescribing medications, participation in a mentoring program**

# Dissemination & Implementation

*Hardest Step!*



# It Takes a Village!!!

- National Mental Health Advisory Committee (sponsored by CFF)
- Investigators for TIDES study & International Guidelines Group
- CF Foundation for funding 138 MHCs!
- CF Australia for inviting us

*Thank you!*