



## So Glad You Asked: Patient Perspectives

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IPAC-RS 2008 Conference



IPAC-RS 2008 Conference

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## Expectations

- § Realistic and mutually agreed upon goals
- § Roles and responsibilities
- § Daily symptom diary, medications, peak flow meter
- § Scheduled appointments replaced urgent care
- § Specific measurable results I could see each day and celebrate with medical care providers

## Beliefs, Behaviors and Outcomes

- § Information became the power over symptoms
- § Uncertainty and fear was replaced with strategic planning and early response
- § Rollercoaster symptoms were eliminated as we learned how to identify and address causes

## November 1985

- § The *MA Report* – *flagship publication makes news headlines*
- § National television and radio coverage
- § Thousands of patients and parents seek help

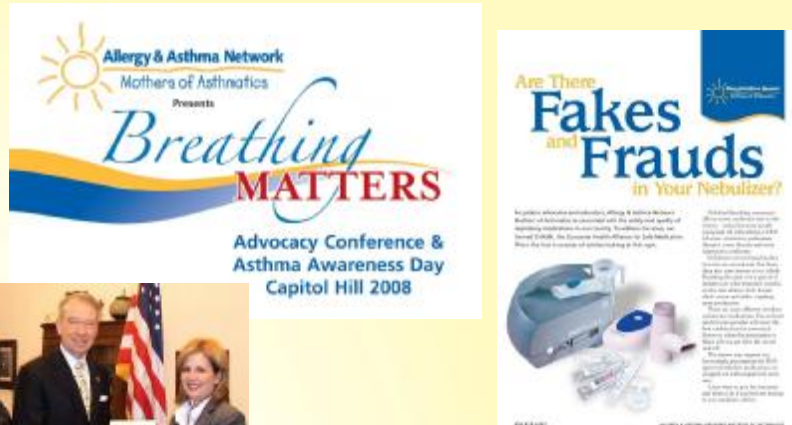
## Education Advocacy Outreach

- § National guidelines are patient centered
- § FDA published dose-counting/indicator guidelines for MDI manufacturers
- § AANMA's annual Asthma Awareness Day Capitol Hill events inspire lawmakers; bills become law
- § CMS stops paying for and illegally mass manufactured compounded nebulizer medications

## Education Advocacy Outreach



## Education Advocacy Outreach



## Keys to Success

- § Listen
- § Innovate
- § Test
- § Distribute
- § Measure
- § Listen again
- § Improve

## Real World

- § Patients don't want to be sick
- § They want what you have but on their terms
- § Effortless
- § Free of visible impairment  
(medications and devices)
- § Sans the side effects
- § Just like everyone else

## Compliance is a One Way Street

- § Doesn't work
- § Requires an omnipotent medical professional to identify the perfect therapy and device for a passive patient
- § Assumes that the patient has been given enough information in a digestible format and
- § It can be readily incorporated at home, school and play

## Predictable compliance failures

- § As needed
- § Outgrow
- § Mild, moderate, severe
- § Long term, long acting, short acting, quick relief, fast acting
- § Controller
- § Rescue

## Question:

- § What is the best aerosol delivery system for patients?
- DPI
  - MDI
  - MDI w/holding chamber
  - Nebulizer

## What Patients Said

- § Wanted a hybrid MDI – Nebulizer w/means of keeping track of doses
- § Affordable unit dose
- § Insurers to cover without requiring a death defying trip to the hospital
- § No side effects
- § Less nebulization time
- § Combination medications



## Dose Counting

- § Running on empty
- § How many have died or suffered
- § No other drug runs out without warning
- § How long and how many lives will be impacted before innovation and technology catch up to patient need?

## MDI Transition

- § 20 years ago: CFCs are banned
- § Medical exemption
- § December 31, 2008 - First time in history FDA removes safe and effective drug from market
- § Public relations failure
- § Needless anxiety

## MDI Transition

- § Analog to digital television vs. CFC to HFA transition
- § Affects 40 million MDI users with life threatening conditions
- § No precedence, no transition plan for patients and caregivers, no response team
- § No united effort among federal agencies, nonprofits and pharma

