Federally Funded Hemophilia Treatment Centers

340B PROGRAM AND COMPREHENSIVE CARE

PANEL PRESENTATION
MID ATLANTIC/REGION III ANNUAL MEETING
MARCH 27, 2015

340B Programs

- Veterans Health Care Act of 1992
- Section 340B limits cost of drugs to certain grantees of federal agencies
- Significant savings on pharmaceuticals may be seen by those entities who participate in this program.
- Program administered by the Office of Pharmacy Affairs (OPA) of HRSA, under the federal Department of Health and Human Services (HHS).
- Federally Funded HTCs qualify
  - Income considered federal money and subject to federal rules and oversight
340B and HTCs

- HTCs encouraged by federal agencies to enroll
  - Offset decreases in federal funding
  - Expand staff and services to meet increased needs and expansion of patient populations
  - Increased services to women
- ALL profits (Program Income) are required to go to the HTC
  - Cannot be used by hospital or institution for other uses
  - Cannot be used to offset inpatient losses
  - MUST be used to further goals of MCHB Hemophilia Program
- Significant oversight required
  - Annual reports of income and use of income required

Mid Atlantic/Region III Trends

ENROLLMENT AND INCOME
### 340b Programs

- 13 Regional HTCs enrolled in program and certified
- 11 Active
- 2 Enrolled but not yet active
- 1 not enrolled
- 1 New active program

### HTC Staff in Region Supported by 340B

47 FTEs of HTC staff supported by 340B in our Region

- Physicians: 5.75
- Nurses: 18.5
- Social Workers: 6.4
- Physical Therapists: 1.25
- Other Program Staff: 15.1

Also, research studies funded: 8
Concerns about Program Income

- **Patient enrollment**
  - 34% of regional patients with hemophilia
  - Likely lower due to some other patients enrolled
  - Increasing numbers of insurers allowing choice
  - Major for profit companies have most contracts
  - Patients and family members hired by companies to “advocate” or educate peers about services

- **Income is down**
- **No decline in patient enrollment**
  - TBD: Factor units distributed
  - Milder patients, lower factor use?

The Patient Experience: Consumers’ Perspective

MIKE CLANCEY
STEVEN LAMPE
Regional 340B Programs

ARE CENTERS PROVIDING SUFFICIENT AND TIMELY INFORMATION TO PATIENTS AND FAMILIES?

340B PROGRAMS

- HTCs follow required Patient Choice Policies
  - Relate to product choice and choice of factor supplier
  - Consciously avoid exerting any pressure or perception of enticement
- Staff want to provide care, not marketing or sales
- Centers do not highlight source of funding for staffing, programs or services as coming from factor distribution program
REC CONSUMER PERSPECTIVE

- Well educated, engaged consumers report not understanding importance/goals of 340B programs
  - Center staff concentrate on clinical issues and may not inform patients of the role of 340B program in supporting comprehensive care.
- REC Consumers initiated and developed educational brochure for patients and families about benefits of 340B

REC Developed 340B Brochure

Frequently Asked Questions

- How does using a 340B program benefit me?
  - When you buy a covered factor from your 340B site, you are helping to make sure that the center has enough funds to continue providing the best possible care for you and your family.
  - The center also provides you with a receipt. You can use this receipt when you file your insurance claim. Your center staff can assist you with this process.

Do I have to change my ordering factor from the one that I currently use to the 340B program?

- No, you should be able to get the same factors that you are using now.

Does the pricing of the factor cost more if I use it through the 340B program?

- Actually, since 340B purchases factor at reduced rates, your cost may be less.

What if I switch to the 340B program from my current ordering factor?

- Switching from the 340B program will vary by factor. You should contact your center staff to determine the specific requirements for switching factors.
Personal Impact of Comprehensive Care

MIKE CLANCEY
STEVEN LAMPE

Care before HTCs

- Diagnosis
  - Often delayed
  - Based on series of symptoms
  - Misdiagnosis not uncommon
  - Very difficult for mild or moderate hemophilia

- Limited Treatment Options
  - Emergency Room based treatment
  - Constant provider education issues
  - Treatment often delayed
Education of Providers

- Physicians trained in Hematology/Oncology
  - Few specialized in hemostasis
  - Interested providers sought their own information and education
  - No team support or resources
  - Education of emergency staff almost always fell to patients or parents (Patient advocates in ER at 3 AM!)

Before HTCs

- Resources were scarce
  - Each family identified resources available to them and helped themselves
  - Moving to new area quite challenging
    - Needed to start all over again with advocacy and provider education, locating and establish new resources
Lack of Comprehensive Care

- **Medical care**
  - Usually primary care provider
  - Dentists and other specialists required education
  - Treatment usually in ER
  - Long waits; delayed treatment
- **No team support**
  - No specialized nurses, social workers or PTs
  - No comprehensive patient/family education
    - Support and education provided by NHF and other organizations
  - No home treatment
  - No education of schools, employers
  - No advocates for patients and families
  - No coordination of care

Results before HTCs

- Frequent bleeding
- Joint disease
- Pain
- Eventual disability
- Isolation: significant absences from school and work
- Limited ability to travel, work, play
- Studies and research limited
Our Own Stories

LIFE BEFORE COMPREHENSIVE CARE

Advent of HTCs

- Multi-disciplinary approach to care
- Coordination of care
- Concentration of expertise in bleeding disorders
- Team dedicated individuals with bleeding disorders
- Laboratory monitoring
- Access to research studies and surveillance
- Education of healthcare providers, ER, schools, etc.
- Whole team in one visit: convenience, one co-pay
- Insurance assistance, educational programs, referrals to appropriate specialists
How Life Got Better for us

CARE AT AN HTC

Multi-Disciplinary Team

- **Physicians**: hematologists specializing in bleeding disorders with many patients and experience
- **Nurses**: trained and experienced in hemophilia; provides education, assessment and treatment
- **Social workers**: trained and experienced in resources; works with you and your situation
- **Physical Therapists**: understands limitations, design fitness and rehabilitation program to fit your needs and abilities
- **Genetic Counselors**: on staff or by referral
- **Research staff**
Thanks for the history lesson...
So what?

- Federal funding had no increases for years
  - Funding has fallen significantly in last 8 years
  - MCHB encourages HTCs to use 340b factor programs to supplement funding to keep HTCs viable.
- Best way to increase financial health of HTCs is through factor sales
- Profits required by law to go back to HTC to support comprehensive care and programs

Challenges with 340b Programs

- Decreased Program Income recently
- Pressure from hospitals who can’t keep income
- HTC staff don’t push patients to use 340b Program; want to maintain patient choice
- HTS staff are not sales people
  - Lack of advertisement about 340b income to support staff, programs and research
  - Many patients are not well informed about importance of 340b Programs
  - Some patients do not know of risks of failed 340b Program
Patients’ Role in the Solution

- Many patients do not have a choice of home care provider
- But, for patients with a choice, they should think about what an HTC means to them when deciding where to get their factor

The Future: Five Years Away at Current Trends?

- If 340b Programs fail or close:
  - Patients will need to find a medical practice with a hematologist available
  - Unlikely to have expertise in hemophilia
  - Distance becomes more of an issue
  - You may still get factor; is that all you need?
Do you need your HTC team?

- You may have a nurse, but
  - Will they be experienced in hemophilia?
  - Will you rely on a home care nurse, primary care nurse, emergency room nurse or a temp?
- You will be unlikely to have a social worker in primary care or ER
  - You will need to seek counselor separate from hemophilia care
  - Unlikely to have resources or experience with meeting your needs
- You will be able to get a referral for PT
  - Likely a private practice
  - Unlikely to have expertise in hemophilia or your special needs
- Genetic Counselor:
  - Possible referral to a genetic counselor, but may not have experience with current state of hemophilia care.

The Future

- Insurance problems?
  - The internet has thousands of helpful hints; start surfing!
- Factor? No problem! Dozens of specialty pharmacies
  - Which product? Who will help you decide?
- Need surgery or dental work?
  - Who will coordinate the plan to make sure you are safe?
  - How will you find the experienced providers?
- Questions or concerns about symptoms or a bleed?
  - The ER is always open
### The Result?

- Patient and family workload increases
- Quality of care decreases
- Increased stress
- Support will be gone
- No coordination of care
- Outcomes will be worse
- All of the progress that has been made over the past 40 years will begin to unravel

### Conclusion

*This isn’t Fear Factor, it is simple economics.*
Recommendations

- Use consumer developed brochure in clinic; educate patients and families about funding and goals of 340b
- Reach out to NHF chapters and other consumer groups
  - Ask them to highlight need for 340B Programs
  - Encourage education of consumers
- Encourage pharmacy to pursue additional contracts
- Highlight source of funding for materials, programs and services
  - Tag lines on agendas, newsletters, websites, etc.
- Review annual reports from pharmacy carefully to identify increases in staff, pharmacy and overhead expenses

Thank you, REC Consumers!

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