Improving quality of *life*...until a cure...through

- **L**ower mortality
- **I**mproved outcomes
- **F**ewer hospitalizations
- **E**ducated independent patients

Appendix 1
2000, Soucie, et al Mortality in hemophilia
1998, Nuss et al, Medical care in hemophilia
Comprehensive Hemophilia Care in U. S.

- Established in 1975 –
  - Congressional funding for treatment centers
    (Section 1131 of the Public Health Service Act)

- Model for Specialty Disease Management for fragile population
  with costly rare disease

- Grant funding—intended to fully fund public health clinics
  - Centers for Disease Control & Prevention
  - Maternal & Child Health Bureau (Health & Human Services)

- Currently 143 funded centers in 48 states, primarily university settings

APPENDIX 2
1984 Article on Benefits of Comprehensive Care Center
1977 Program Requirements for Grants for Hemophilia Treatment Center
Scope and Mission of Maternal Child Health Bureau
Comprehensive Hemophilia Care in U. S.

- **Scope of Patient Population (See Hemophilia Data Set)**
  - Incidence = 1 in 5,032 live male births
  - Nationally = 25,460 patients
  - Denver = 387 patients

- **Current environment**—flat funding history, increased costs, increase in patients and services—funding is only supplemental to infrastructure that provides services not available in fee-for-service environment

- 1992—Section 602 of Public Law 102-585, the “Veterans Health Care Act”, enacted section 340B of “PHS Act”, and enabled public hospitals, community health centers, HTC’s and other safety net providers to purchase outpatient pharmaceuticals at discounted rates:
  - To extend federal dollars
  - To expand pharmaceutical care
  - To lower patient cost and extend insurance benefits
  - To maintain and/or expand services of HTC

**APPENDIX 3**
- 1998 Article on Occurrence of Hemophilia in the United States
- 2002 National Hemophilia Data Set from CDC
- 2002 Colorado Hemophilia Data Set from CDC
Hemophilia Care: Colorado--2003

- Based at University of Colorado Health Sciences Center
- Established by Colorado law in 1973 (HB 1511, § 1)
- Federal funding began in 1976 (PHS Act 42; 216, 300c-21)
- Funding from Colorado state legislature & federal agencies continues to 2003.

APPENDIX 4
1973 Colorado Statute establishing MSRHTC in Colorado
Mission Statement of University of Colorado Health Sciences Center
ORGANIZATIONAL STRUCTURE OF MSRHTC IN COLORADO

State of Colorado

Board of Regents, UNIVERSITY OF CO HEALTH SCIENCES CENTER

Academic Schools

UCH

Affiliates & Institutes (TCH, NJH, etc)

UPI

SOM

Other schools

MSRHTC

Other schools
MSRHTC Funding Sources

- MCHB
- CDC
- PRIVATE DONATIONS (patient assistance)
- PROGRAM FUNDRAISING (camp, etc)
- RX STUDIES
- RESEARCH GRANTS
- PHARMACY
- STATE of CO

$
Mission of the MSRHTC

- Identify persons with hemophilia and thrombotic disorders

- Provide comprehensive diagnostics, treatment, education, and consultative services for physicians, patients and their families

- Provide educational programs for professional and paraprofessional individuals involved with bleeding disorder care

- Assess and provide treatment for the long-term complications of hemophilia including inhibitors, liver disease, AIDS, and psychosocial issues

- Advance knowledge through research in coagulation disorders
MSRHTC Multi-Disciplinary Team

- Physicians
- Nurses
- Physical Therapist
- Social Worker
- Pharmacists
- Reimbursement counselors
- Administrative staff
- Adjunct staff: Orthopedics, dental, genetics, coagulation lab, infectious disease, hepatology, radiology
Mountain States Regional Hemophilia & Thrombosis Center
Organizational Chart

- Marilyn Manco-Johnson
  Director

- Brenda Riske
  Clinic/Research Director

- Judy Primeaux
  Pharmacy Director

- Clinical Care
  Sue Geraghty
  KC Clevenger
  Sharon Funk
  RA Kirschman
  Sheryl Giambartolomei
  Erin Stang

- Research
  KC Clevenger
  Sheryl Giambartolomei
  Linda Jacobson
  Ruth Ann Kirschman
  Brian Miller

- Administration
  Pat Casias
  Miki Harkin

- Accounting
  Lynn Magnuson

- Pharmacy
  Mark Hagan
  Candice Murchison
  Gayle Ferrell
  Julie Christian

- Adult Hematology: Sally Stabler
  Kathy Hassell
  Jerry Weidel
  Eric Miller
  Carol Walton

- Orthopedics: Amy Beck

- Genetics:
MSRHTC Services

- Clinical
- Pharmacy
- Research
Clinical Services

- Diagnosis
- Treatment – in/ & out-patient
- Education and Disease Management
- Comprehensive multi-disciplinary clinic
- Specialized lab testing
- Genetics – education, prenatal testing
- Dental care—evaluation, education
- Physical therapy
- Psychosocial support, crisis intervention, transitions, support groups, direct counseling
- Coordination of care at other institutions
- Patient Support Programs (camp, etc)
- Integration of factor distribution with treatment
PHARMACY MISSION

MSRHTC RX

- Lowest cost provider

- Non-profit, public sector perspective: produce minimum profit necessary to maintain services and programs of HTC

OTHER RX PROVIDERS

- For-profit, private sector perspective: Produce maximum profit necessary to reward stockholders

Appendix 5
1995 – 2000 MSRHTC Pharmacy cost savings
# Pharmacy Mission

**Pharmacy Mission**

<table>
<thead>
<tr>
<th>MSRHTC RX</th>
<th>OTHER RX PROVIDERS</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Provide care regardless of source of payment</td>
<td>- Provides no uninsured care. Expects total payment from patient and insurer</td>
</tr>
<tr>
<td>- Procure product donations through mfrs, linked to other HTC’s</td>
<td></td>
</tr>
</tbody>
</table>

**MSRHTC RX**

- Provide care regardless of source of payment
- Procure product donations through mfrs, linked to other HTC’s

**OTHER RX PROVIDERS**

- Provides no uninsured care. Expects total payment from patient and insurer
PHARMACY MISSION

**MSRHTC RX**

- Provide Chronic Condition Compassionate Collection policy
- Longevity and stability in the market based on state, federal and university mission and commitment.

**OTHER RX PROVIDERS**

- Pursue full collection of patient balances
- Longevity and stability in the market dependent on profits and economic conditions of private sector
DRUG PRICING METHODOLOGY

**MSRHTC RX**

- FIXED-COST BASIS
  - Acquisition cost + fixed overhead price per unit

**OTHER RX PROVIDERS**

- % BASIS
  - Acquisition cost + % mark up over cost or % discount off AWP

Appendix 6
MSRHTC Price list
United HealthCare price list
1995 – 2002 Pricing analysis, over time
DRUG PRICING METHODOLOGY

MSRHTC RX

- Allows for product selections based on therapeutic benefits, not profit. Equal overhead distribution across all factor concentrates.
- As pharmacy volume increases, overhead decreases, price per unit decreases

OTHER RX PROVIDERS

- Encourages use of product with greatest margin spread. Higher cost products absorb all overhead.
- Increased volume yields same price
## DRUG PRICING METHODOLOGY

### MSRHTC RX

- Allows pass through of manufacturer cost reductions on quarterly basis
- Further reduction on severe high utilization patients—"threshold pricing" caps profit for HTC

### OTHER RX PROVIDERS

- Annual contract price
- High utilization yields more profit
SERVICES

**MSRHTC RX**

- 24/7 pharmacist, physician, nurse availability

- 24/7 product availability with multiple delivery options (local courier, FedEx, UPS, USPS, Greyhound Bus, State Police, Emergency Volunteer Services, Counter-to-Counter Airlines)

**OTHER RX PROVIDERS**

- 24/7 pharmacist availability

- Delivery limited to standard overnight options
SERVICES

**MSRHTC RX**
- Local access for immediate treatment of bleeds of moderate/mild patients on outpatient and inpatient basis (72% of patients are not on home care)

**OTHER RX PROVIDERS**
- 24, 48 or 72 hours availability (delayed treatment produces poorer outcomes)
Customized dosing determination (±/− 5%) capability based on assay availability and HTC pharmacy integration into HTC (ability to evaluate half-life and recovery data on individual patients)

Provides assays in inventory, up to 20% variations
SERVICES

**MSRHTC RX**

- Vital team member for compliance monitoring and adherence.
- Weekly case conference with team. Able to incorporate psychosocial knowledge of patient and family into effective factor management.

**OTHER RX PROVIDERS**

- Receives only prescription information. Not incorporated into broader medical picture of patient and family.
SERVICES

**MSRHTC RX**

- Infusion supplies for each patient, customized as necessary. Customization contributes to compliance.

- Utilization reports necessary to evaluate treatment and compliance provided to HTC team at any time.

**OTHER RX PROVIDERS**

- Standard formulary supply list

- None or unknown
SERVICES

MSRHTC RX

- Local depot for other institutions -- coordinates procurement and/or provides factor to local institutions
- High priority in supply chain during shortages

OTHER RX PROVIDERS

- None
- Lowest priority
SERVICES

MSRHTC RX

- Provides clinical research drug management and distribution for local and national studies

OTHER RX PROVIDERS

- None

Appendix 7
1995 – 2002, MSRHTC Pharmacy and Research product savings
Research Services

Clinical research studies
- Improved products for treatment -- Not experimental
- New technology for delivery of care
- Viral safety improvements

Outcomes research
- Joint outcome study
- Radiological evaluation
- Hemophilia Utilization Group Study
- Quality of Life
- Satisfaction surveys
- Radiosynoviorthesis

Appendix 8
- 2002, abstracts World Federation of Hemophilia—economic issues
- 2002, MSRHTC satisfaction survey
Benefits of Service Integration

- Better health care outcomes
  - Delayed treatment leads to poor outcome
  - Customized/individualized care
    - Maximizes use of product and services
  - Clinic visit vs. ED or hospitalization
  - Better follow-up
Conclusion

What can United do to control costs and receive maximum value for healthcare dollars spent?

- Utilize integrated HTC and HTC pharmacy
- Require medical evaluation and utilization management by the MSRHTC for all patients
- Promote and support the application of HTC treatment recommendations and factor coordination on patients treated outside UCHSC system
- Become active medical partner in management of difficult patients