

# Down Syndrome *Information Network* of the Twin Tiers

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## LENDING LIBRARY

### HELLO SPRING!

The crocuses and daffodils are blooming, the playgrounds are bustling and baseball is starting!

**STARWISH BASEBALL SIGNUPS** are every Saturday in April at Chapel Park, Pine City from 10am-1pm.

The **STARWISH BASEBALL LEAGUE** is for children 5 yrs -21 yrs, who have any disability that prevents them from playing or being successful in a typical league. Fee \$25.00 (scholarships available). Games will begin in June. For questions call Elaine Lepkowski 739-8849.



Any suggestions for materials to be purchased for our lending library would be greatly appreciated. It could be books, videos, software or educational materials suitable for adult or child use. Ideas can be submitted to Marcel Sadler at Chemung ARC, [mks@chemungarc.org](mailto:mks@chemungarc.org)

## March Madness Success

Our pizza party and talent show in March was lots of fun, about 30 people attended. We were entertained by guitar playing, singing and dancing. It was so much fun, we may have to do it again. Our new microphone and amplifier got a real workout.



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**Next Meeting:**

*6pm April 27, 2005*

## Agenda

1. Introductions
2. Open Discussion and Sharing

# MOTHERS HAVE SPOKEN

PHYSICIANS NEED TO DO A BETTER JOB IN DELIVERING A POSTNATAL DIAGNOSIS OF DOWN SYNDROME.

*According to an article in Down Syndrome News vol 28, no 1, nearly 3000 mothers were recently surveyed on how they learned that their new baby had Down Syndrome and what support was provided with this diagnosis. The report calls on physicians to adopt 10 recommendations when delivering a diagnosis of Down Syndrome:*

1. The diagnosis should be delivered by a physician.
2. Obstetricians, neonatologists and pediatricians need to coordinate their efforts in providing information to the family.
3. The news should be delivered once the mother is settled and as soon as a physician suspects the diagnosis.
4. Whenever possible the physician should make the announcement with both parents present in a private setting.
5. When delivering the news about Down Syndrome, the physician should first congratulate the parents on the birth of the child and provide information including positive aspects of the condition.
6. Health care professionals should provide sound medical advice based on up-to-date information and keep their personal opinions to themselves.
7. Mothers should be provided with up-to-date printed materials or at least a list of resources where such material can be found.
8. Parents should be provided access to other families who have children with Down Syndrome. A first call program could be coordinated by hospitals and local support groups to provide this service.
9. A private hospital room should be offered after the diagnosis is initially disclosed.
10. Physicians should be cognizant of the realities and possibilities of growing up with Down Syndrome. They should possess real life knowledge, not just what was taught in medical school, of the potential of individuals with Down Syndrome.

*Feel free to share these recommendations with your healthcare providers.*

## Dates to Remember:

### **April 27, Wed**

Monthly Meeting / Chemung ARC / 6pm

### **May 26, Wed**

Monthly Meeting / Chemung ARC / 6pm

### **July 16**

Summer Picnic Thorne St Park / Horseheads / 12-5pm

### **September 24, Sat**

2nd Annual Buddy Walk and Chemung Canal Fall Festival

*Meetings of the Down Syndrome Information Network of the Twin Tiers are held on the fourth Wednesday of every month (unless otherwise announced) at Chemung ARC, 711 Sullivan Street in Elmira.*