



THE **MARFAN**
FOUNDATION

Know the signs. Fight for victory.

HEALTHY MARFAN LIMBS FEET & SPINE

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 THE **MARFAN**
FOUNDATION

ANNUAL CONFERENCE

TOPICS

Feet

Ankles

Quality of Life

**Patients with connective tissue disorders are
living longer than ever!**

...SO WHAT!?!?!?!?

- High traffic'd area
- Many things active
- Lots of things can go wrong



FOOT & ANKLE

- **Frequently flattened arches**
- **Pes planus**
- **Elongated digits**



BITTERMAN SHOEWEAR PEARLS

- Shoes with low heels
- Well-cushioned soles
- Stiff soles
- Broad toe boxes
- Sponge wedges --> first web space
- Custom-molded orthotic appliances
 - Resist foot pronation
 - Control hindfoot



FOOT & ANKLE

- **Scant research on reconstruction vs. fusion**
- **Augmentation**



ANKLE

- **“Loose ankles”**
- **Give out**
- **Primary tissue repair vs. reinforcement / cadaver**



QUALITY OF LIFE

Endurance

Strength

Fatigue

Pain

GI

Oral Health

Athletic Restrictions

Cosmetic concerns

Psychiatric

Pregnancy



PAIN

- **Many theories on the true cause**
- **Musculoskeletal**
 - Scoliosis
 - TGF- β & cytokines
 - Dural ectasia
 - Degenerative arthritis from deformity (foot/ankle)



QUALITY OF LIFE

Rao, Sponseller 2016 J Surg Orthop Adv

- 230 patients
- Top concerns – cardiac, back pain, and fatigue
- Clinical manifestations differ amongst individuals → different symptoms
- Quality of life < US Norms
- Most severe pain – 25-45

FATIGUE

- **Limits for social interactions**
- **Inability to function in workplace**
- **Compounds feelings of depression and anxiety**
- **Inability to cope with daily activities**
- **Modification of daily activities**



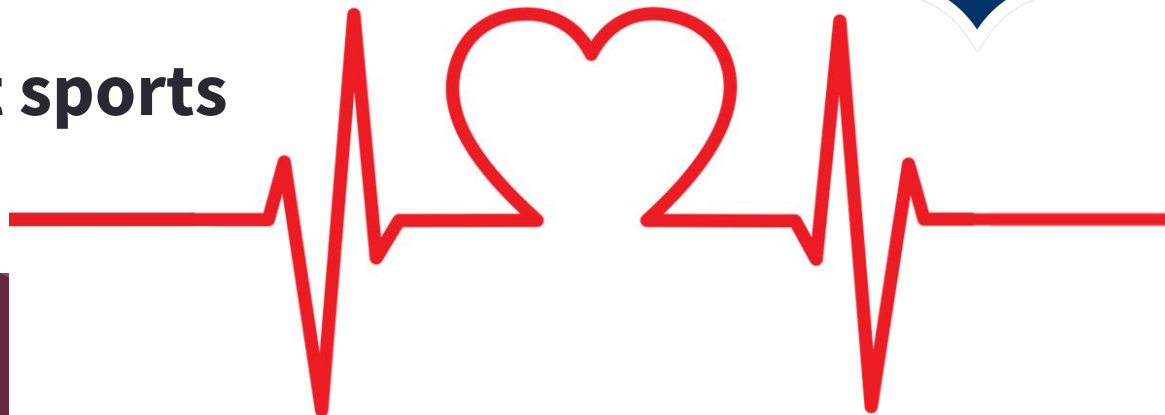
ATHLETIC PARTICIPATION

- Interaction with others
- Mental well-being
- Approach with **CAUTION**
- No one size fits all
- Individual approach to all



ATHLETIC PARTICIPATION

- **Monitor HR**
- **SBP**
- **No exertional activities**
- **Adjust**
- **No general consensus**
- **Contact sports**



SUMMARY

1. **We all must be on the lookout! Everyone!**
2. **All Specialties!**
3. **All shapes and sizes**
4. **Catastrophic consequences if unrecognized**
5. **Multi-disciplinary approach**
6. **Early recognition**
7. **Early treatment**
8. **Equivalent life span!**
9. **Improve quality of life**



Thank You!

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