

Report on “World Duchenne Muscular Dystrophy (DMD) Day” Activities – 7th September 2025

Coordinator: Dr. Varnit Shanker

Organized by: IAP Jaipur Branch in association with Rajasthan Academy of Pediatric Neurology (RAJ AOPN)

World Duchenne Muscular Dystrophy (DMD) Day, observed globally on 7th September, serves as an annual reminder of the need for awareness, early diagnosis, and integrated care for children affected by Duchenne Muscular Dystrophy and related neuromuscular conditions. The 2025 observance in Jaipur, coordinated by Dr. Varnit Shanker, marked a landmark multi-institutional effort that successfully combined medical education, public advocacy, patient engagement, and community awareness.

A series of impactful events were organized in collaboration with the Indian Academy of Pediatrics (IAP) Jaipur Branch & Rajasthan Academy of Pediatric Neurology (RAJ AOPN) and ICON Foundation. The initiative received widespread appreciation from clinicians, parents, advocacy groups, and the media for its comprehensive outreach and evidence-based messaging.

1. Poster Release for Awareness by IAP Jaipur Branch

The event commenced with the release of an official awareness poster by the IAP Jaipur Branch, specifically designed to highlight the key clinical signs of DMD, the importance of early genetic diagnosis and the availability of multidisciplinary management options.

The poster was unveiled at the IAP Jaipur office in the presence of senior pediatricians, neurologists, and postgraduate trainees.

Objective: To visually and simply convey the critical need for early recognition and referral of suspected cases of muscular dystrophy.

Content Highlights: Early red flags (e.g., delayed motor milestones, Gowers' sign), genetic testing pathways, role of physiotherapy, and psychosocial support systems.

Impact: The poster was circulated across over 25 pediatric clinics and hospitals in Jaipur, shared on social media platforms of IAP Jaipur and RAJ AOPN members, and was viewed by more than 5,000 online users within 48 hours.

Outcome: It became an effective visual tool to engage both parents and practitioners in conversations about muscular dystrophy.



DMD Poster released by Jaipur IAP Office bearers, Dr. Atul Shanker (President), Dr. Mohit Vohra (Secretary), Dr. O. P. Bhalodia along with senior colleagues.

DUCHENNE AWARENESS DAY
7 sept 



DUCHENNE MUSCULAR DYSTROPHY



7 September, 2025 DMD Awareness Day
Poster launch by
IAP Jaipur in association with Rajasthan AOPN



Understanding Duchenne Muscular Dystrophy



Duchenne Muscular Dystrophy (DMD) is a genetic disorder causing progressive muscle weakness affecting 1 in 5,000 live male births globally, with 20,000 new cases annually. Mutation in the dystrophin gene leads to a lack of dystrophin protein, essential for muscle health. DMD Primarily affects males; females are typically carriers but may show symptoms. Symptoms appear between ages 3-5, with muscle weakness worsening over time, leading to loss of mobility and respiratory complications.

Early Signs and Symptoms



Symptoms typically appear between ages 3-5. Early Indicators are Delayed milestones: Sitting, standing, walking, Enlarged calves and unusual walking patterns. Difficulty in running, climbing stairs, and using Gower's maneuver to stand, some children experience learning disabilities, including challenges with attention, memory, and emotional interaction. Muscle weakness spreads to arms, legs, and trunk, with respiratory and cardiac complications emerging in the teen years.

Treatment Options for DMD



Prednisone, Deflazacort - Preserve muscle strength, delay progression
Exon Skipping Therapy - Target specific genetic mutations
Gene Therapy - Introduce micro-dystrophin to muscle cells



Supportive Care Strategies



Physical Therapy: Exercises to maintain muscle strength and flexibility.
Orthopedic Support: Braces and corrective surgeries to improve mobility and comfort.
Respiratory Care: Assisted ventilation to address weakened respiratory muscles.
Educational Support: Interventions for learning disabilities and emotional challenges.
Medications: ACE inhibitors and beta blockers to manage cardiac health.

BELIEVE IN STRENGTH BEYOND MUSCLES

2. Participation in National Consensus Meet on DMD and Neuromuscular Disorders (Noida)

IAP Jaipur Branch and RAJ AOPN office bearers, led by Dr. Varnit Shanker, actively participated in the National Consensus Meet held in Noida, where leading pediatric neurologists and genetic experts from across the country deliberated on DMD and other neuromuscular disorders.

Agenda: National strategy for standardizing diagnostic protocols, integration of newborn screening, and consensus on steroid therapy and gene therapy readiness in India.

Jaipur Delegation Contribution: Presented insights from Rajasthan's regional experience in diagnosis and follow-up care.

Outcome: The discussions helped align Jaipur's local practices with national-level consensus guidelines, thereby strengthening the region's approach to DMD care.

Significance: This participation positioned Jaipur as a key academic contributor in the nationwide DMD network, reinforcing the state's commitment to evidence-based pediatric neurology.



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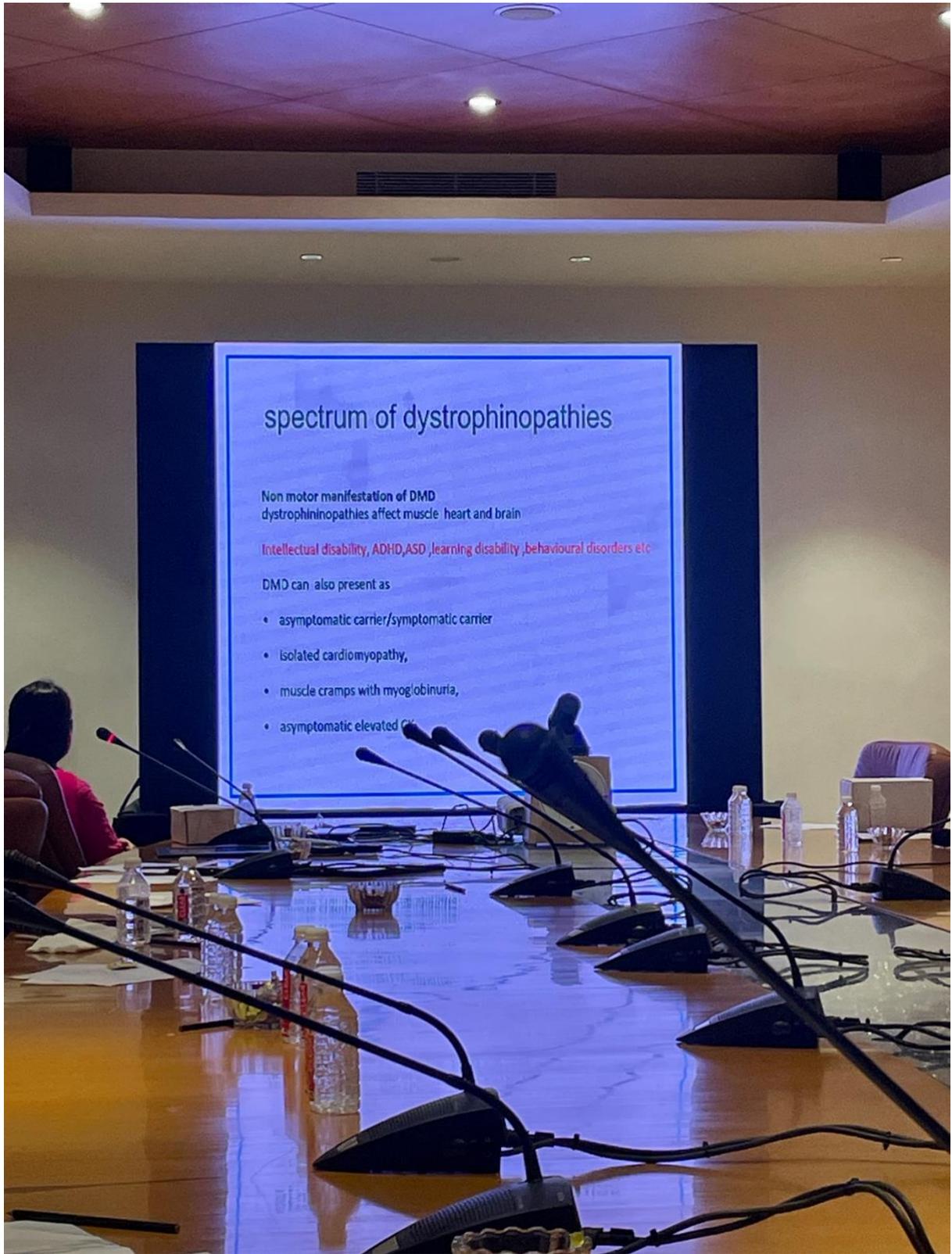
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spectrum of dystrophinopathies

Non motor manifestation of DMD
dystrophinopathies affect muscle heart and brain

Intellectual disability, ADHD, ASD, learning disability, behavioural disorders etc

DMD can also present as

- asymptomatic carrier/symptomatic carrier
- isolated cardiomyopathy,
- muscle cramps with myoglobinuria,
- asymptomatic elevated CK

3. Parent Connect Program at ICON Foundation's CDC

In parallel, the ICON Foundation's Child Development Centre (CDC) hosted a special Parent Connect Program where several children with DMD and their families participated in interactive sessions with therapists, psychologists, and neurologists.

Activities Conducted:

Story-sharing by parents about their caregiving journey, Live demonstration of home-based physiotherapy and sensory integration techniques, Counseling sessions on school integration, nutrition, and assistive device use, Emotional well-being sessions facilitated by psychologists and special educators.

Objective: To provide a supportive platform for DMD families to exchange experiences and receive practical guidance on multidisciplinary management.

Outcome: Parents reported high satisfaction, and the event strengthened the ICON Foundation's role as a leading neurorehabilitation center for pediatric neuromuscular conditions.

Impact: The event fostered a stronger sense of community, reduced parental isolation, and increased awareness of available local resources.



4. CME on Diagnosis and Management of DMD

A Continuing Medical Education (CME) session titled “Diagnosis and Management of Duchenne Muscular Dystrophy: From Clinic to Community” was held for hospital staff and pediatric residents. The event was organized under the academic leadership of Dr. Priyanshu Mathur, Associate Professor and Head of the Rare Disease Department at JK Lon Hospital.

Duration: 2 hours (interactive and case-based)

Participants: Over 70 pediatric residents, physiotherapists, and hospital clinicians from major private and government hospitals in Jaipur.

Core Topics Covered: Updated ILAE-based classification of neuromuscular disorders, Role of creatine kinase (CK) screening and genetic testing, Steroid regimens and emerging therapies like exon-skipping and gene transfer techniques, Importance of multidisciplinary follow-up, physiotherapy, and nutritional care, Learning Outcome: Enhanced clinician awareness about timely diagnosis and structured management, leading to improved referral practices.

Feedback: Participants appreciated the CME’s clarity, clinical depth, and relevance, with several hospitals expressing interest in organizing similar sessions quarterly.



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**Indian Academy of
Pediatrics**
(IAP Jaipur Branch)

There is currently no cure for Duchenne Muscular Dystrophy (DMD).

But treatments are available to

manage symptoms,
slow disease progression,
and improve quality of life.

Physical & Respiratory Therapy, Orthopedic Management, Mobility Aids

Physical Therapy:

for maintaining muscle function and preventing complications like contractures.

Respiratory Therapy:

Helps with breathing difficulties and providing equipment for assisted breathing.

Orthopedic Management

to address scoliosis (spinal curvature) and contractures (muscle tightening)

Mobility aids:

Braces, canes, and wheelchairs can help maintain mobility

Few Gs

Genetic Test – definitive diagnostic confirmation (dystrophin gene mutation).

Gower's Sign – hallmark bedside finding of proximal weakness.

Glucocorticoids – mainstay therapy, slows muscle degeneration.

Growth Delay – short stature and delayed puberty commonly seen.

Gastrocnemius Hypertrophy – pseudohypertrophy of calves, classic clinical clue.

5. DMD Quiz for Pediatricians

To promote academic engagement, a DMD Quiz was organized for IAP Jaipur pediatricians, coordinated by Dr. Varnit Shanker and the IAP academic committee.

Format: 25 evidence-based, clinically oriented multiple-choice questions.

Participation: Over 40 pediatricians from Jaipur and nearby districts.

Topics Included: Clinical recognition, genetic testing interpretation, physiotherapy protocols, and management algorithms.

Objective: To reinforce critical concepts and create a competitive learning atmosphere around a relatively under-discussed but important disorder.

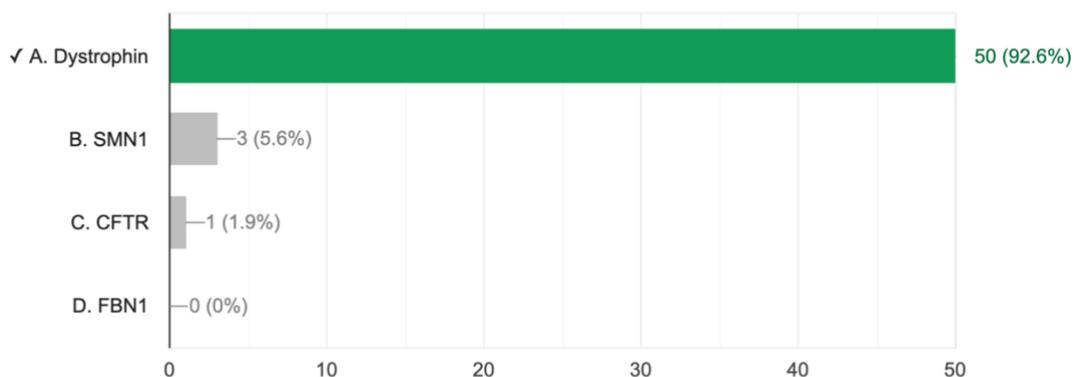
Outcome: The quiz received enthusiastic participation, with top performers felicitated during the closing session. It encouraged practitioners to integrate DMD awareness into daily pediatric practice.

Frequently missed questions

Question	Correct responses
Which exon deletion is most common in Duchenne Muscular Dystrophy?	19 / 52
Which drug is FDA-approved for exon 51 skipping therapy in DMD?	25 / 55
Ataluren is used in DMD patients with:	12 / 51
Which cardiac screening is recommended annually from early adolescence in DMD patients?	17 / 54
Which monoclonal antibody against myostatin is under trial for DMD to promote muscle regeneration?	21 / 47
Which investigational therapy targets micro-dystrophin gene replacement delivered by viral vectors?	19 / 47

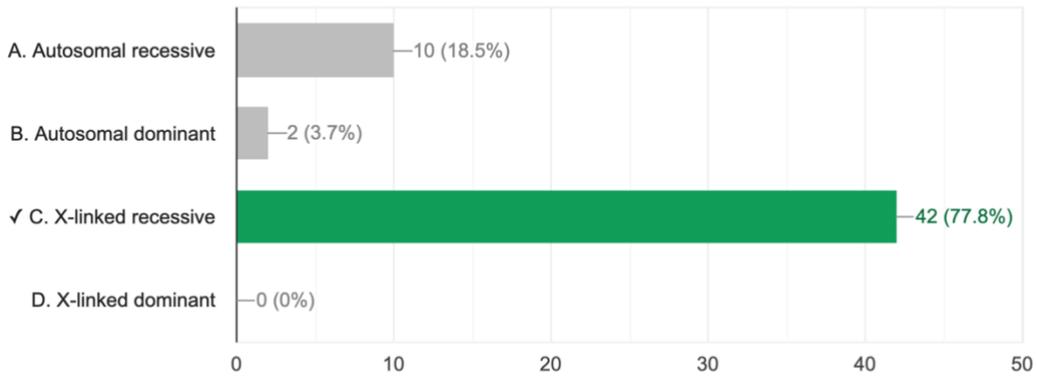
Which gene mutation causes Duchenne Muscular Dystrophy?

50 / 54 correct responses



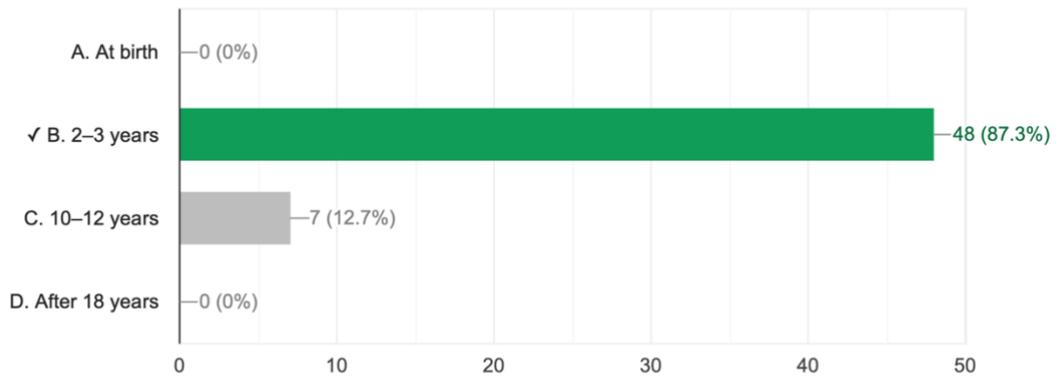
Duchenne Muscular Dystrophy is inherited in which pattern?

42 / 54 correct responses



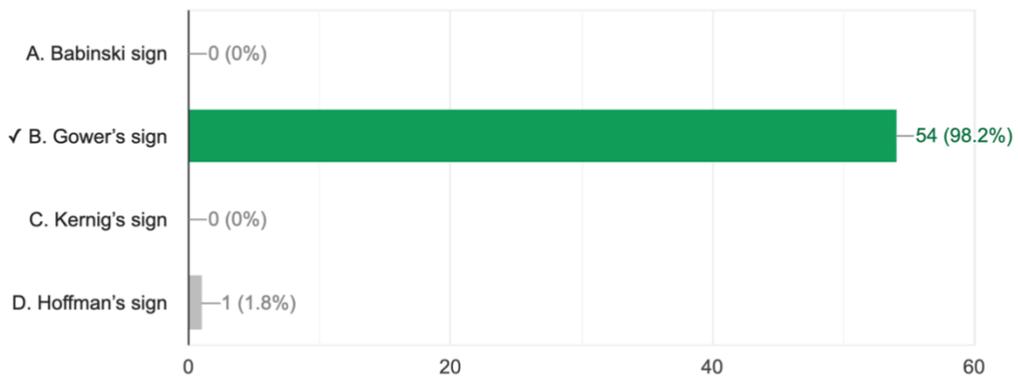
At what age do symptoms of DMD usually become apparent?

48 / 55 correct responses



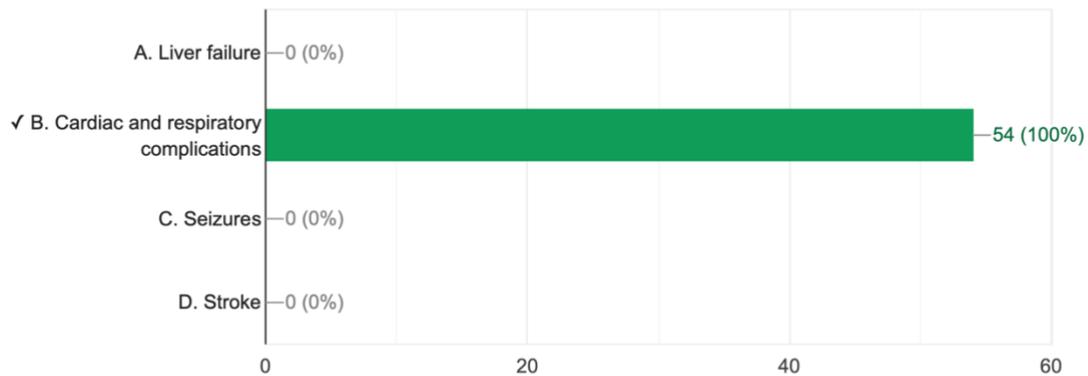
Which clinical sign is classically associated with DMD?

54 / 55 correct responses



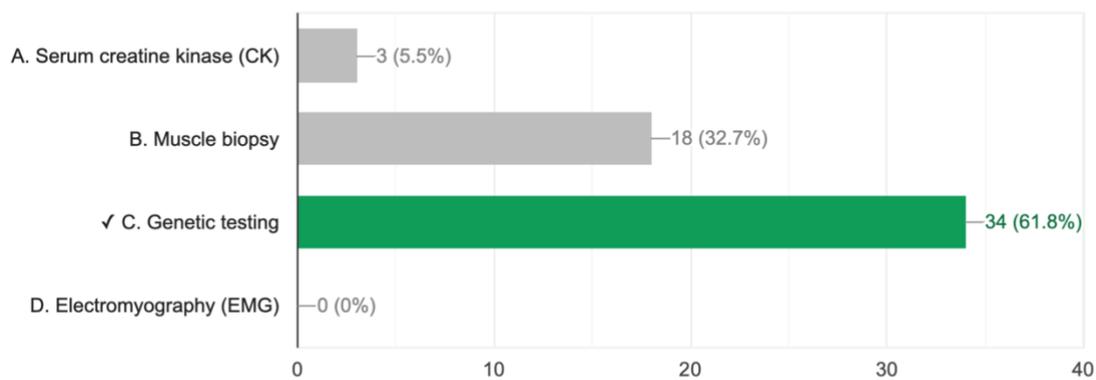
What is the most common cause of death in patients with DMD?

54 / 54 correct responses



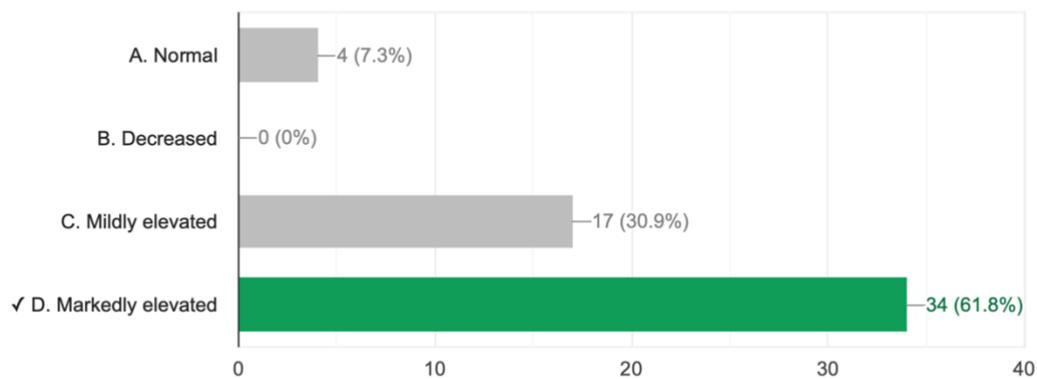
Which investigation confirms the diagnosis of DMD?

34 / 55 correct responses



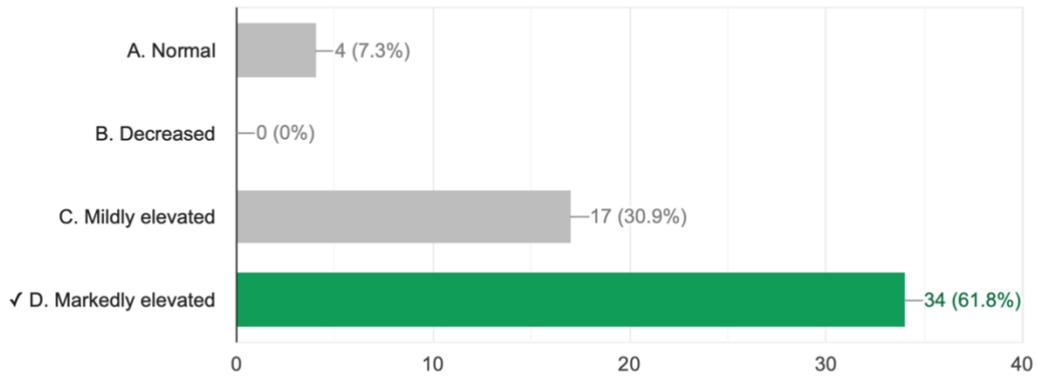
Which of the following is true about serum CK in early DMD?

34 / 55 correct responses



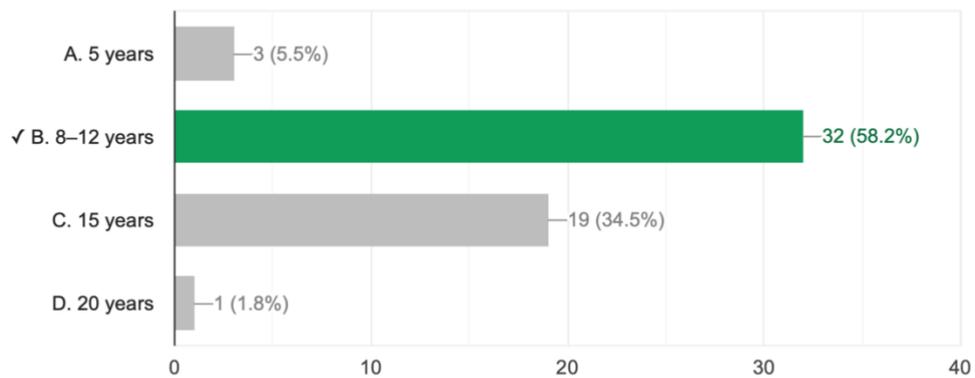
Which of the following is true about serum CK in early DMD?

34 / 55 correct responses



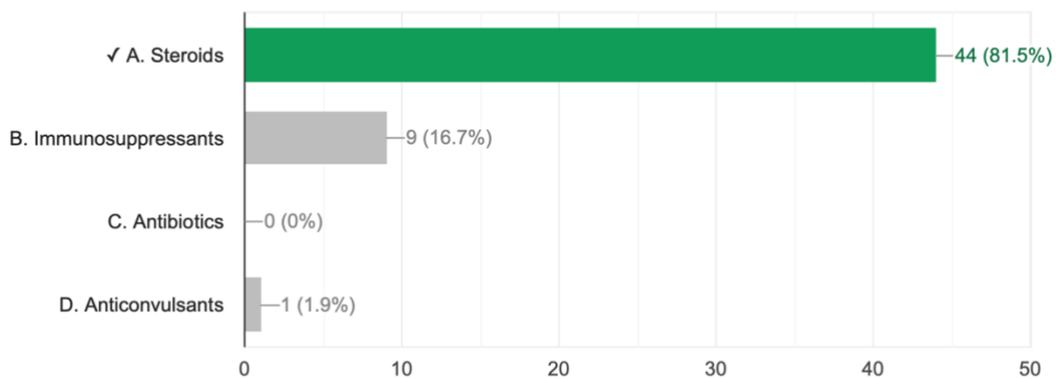
What is the average age of loss of independent ambulation in untreated DMD patients?

32 / 55 correct responses



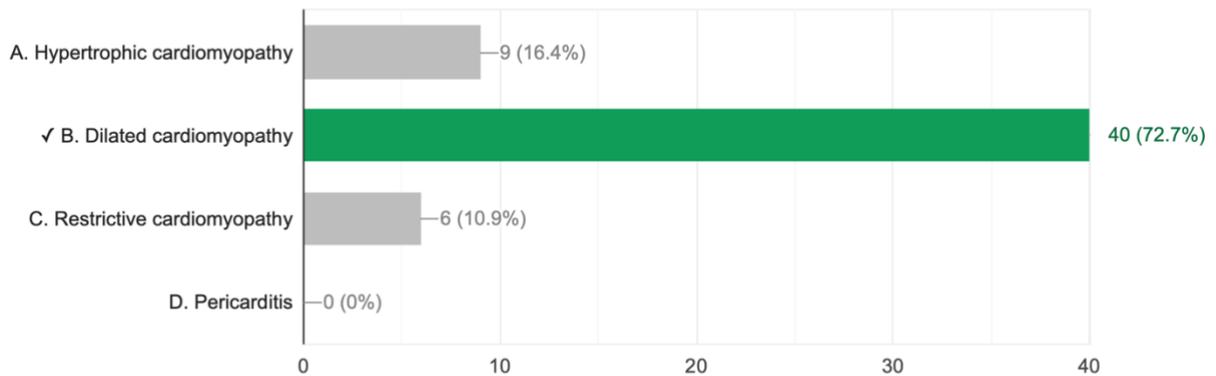
Which drug class is the mainstay of pharmacologic treatment in DMD?

44 / 54 correct responses



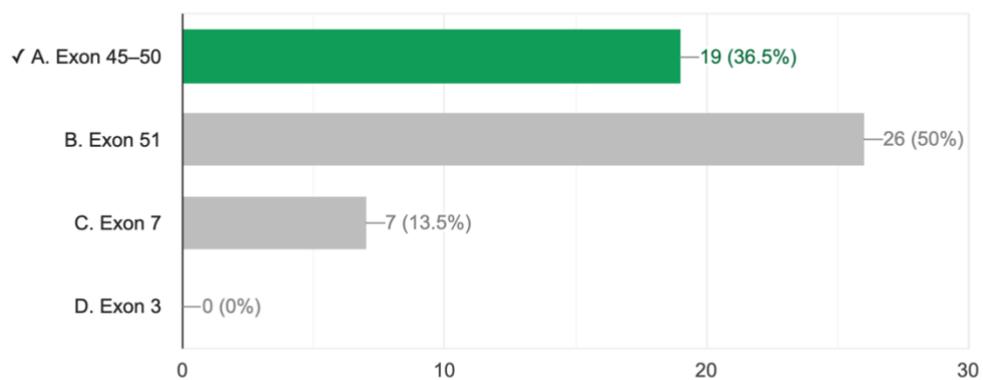
Which cardiac complication is most common in DMD?

40 / 55 correct responses



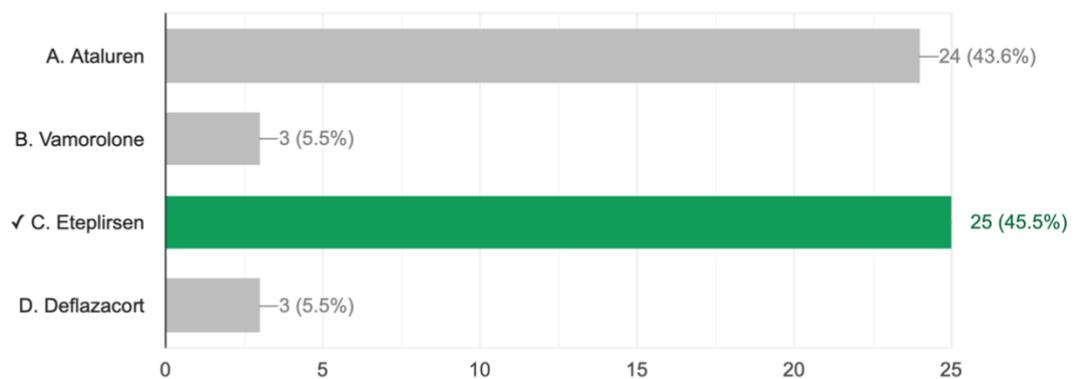
Which exon deletion is most common in Duchenne Muscular Dystrophy?

19 / 52 correct responses



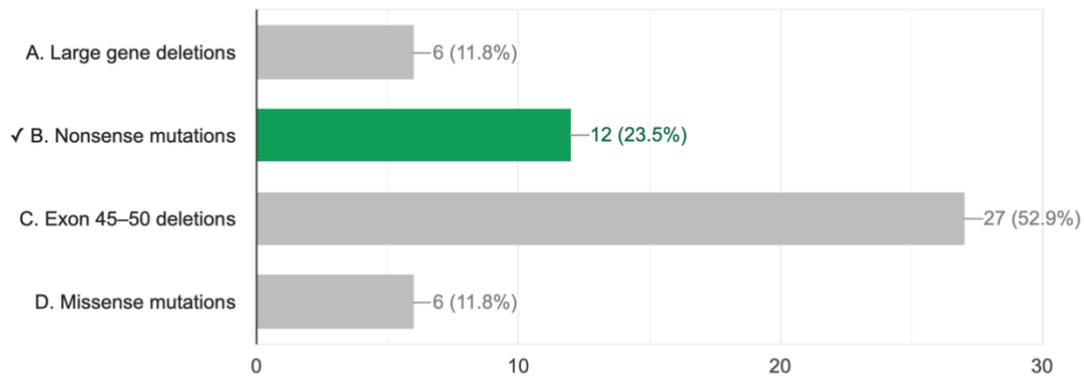
Which drug is FDA-approved for exon 51 skipping therapy in DMD?

25 / 55 correct responses



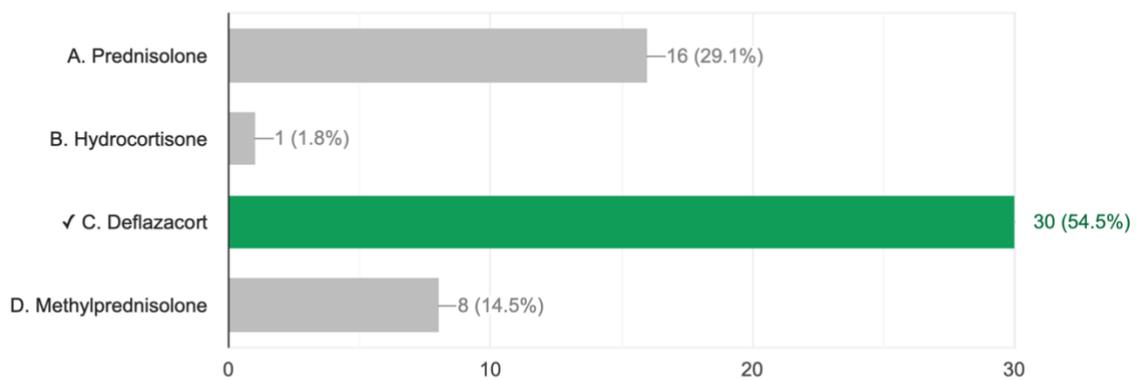
Ataluren is used in DMD patients with:

12 / 51 correct responses



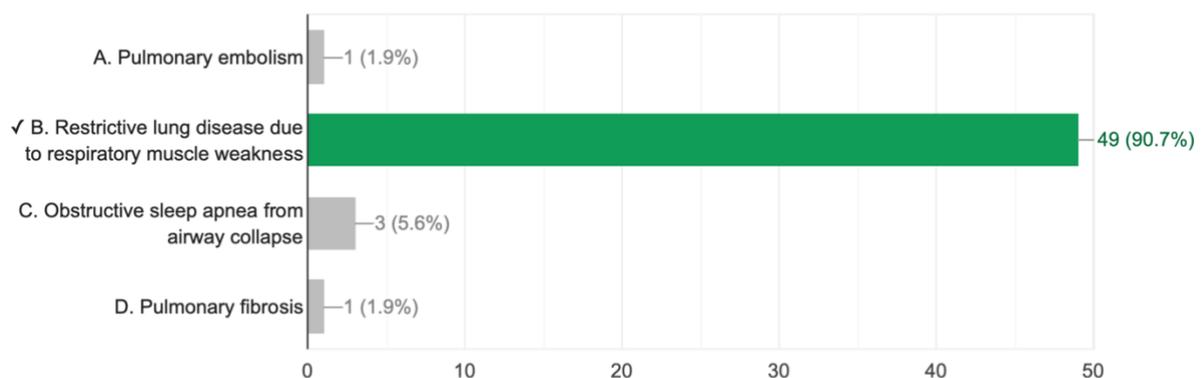
Which steroid is preferred in some guidelines due to a better side effect profile in DMD?

30 / 55 correct responses



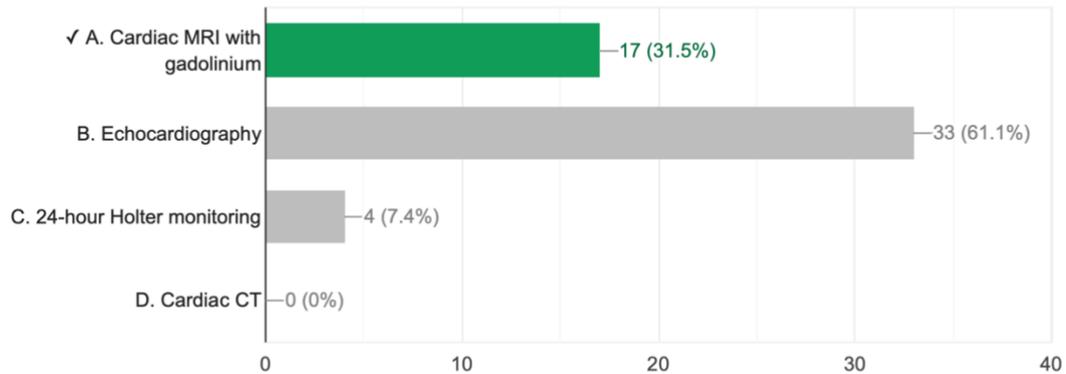
Which of the following is a major pulmonary complication in DMD?

49 / 54 correct responses



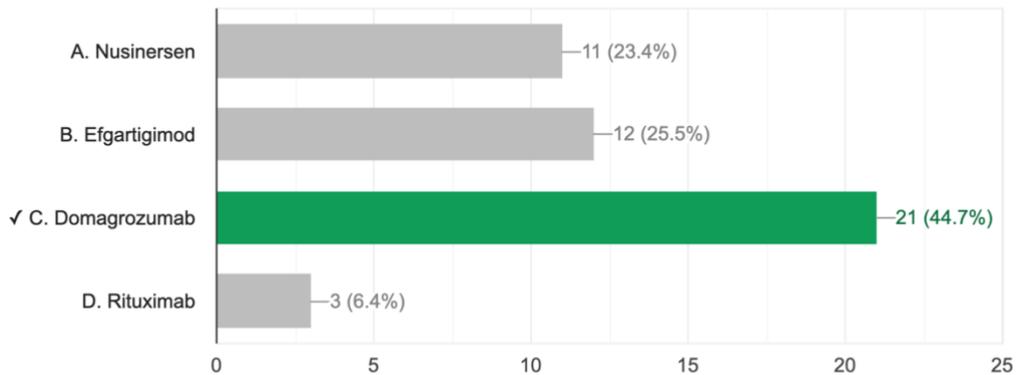
Which cardiac screening is recommended annually from early adolescence in DMD patients?

17 / 54 correct responses



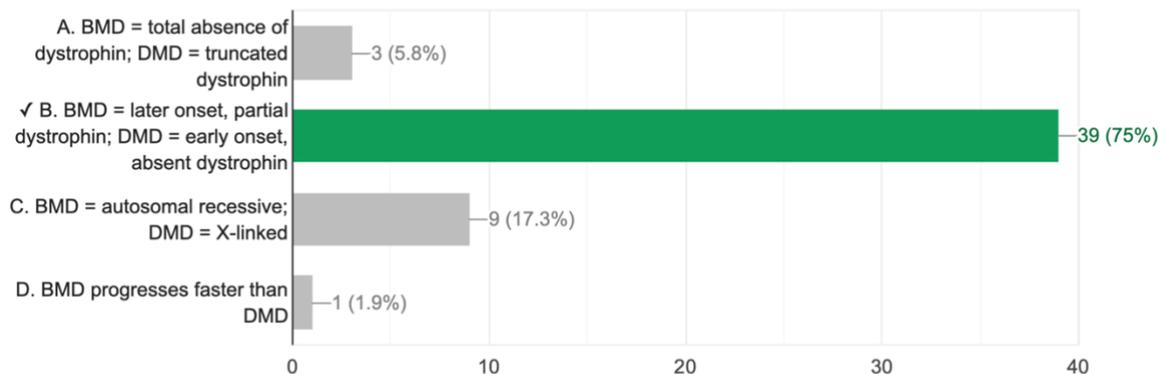
Which monoclonal antibody against myostatin is under trial for DMD to promote muscle regeneration?

21 / 47 correct responses



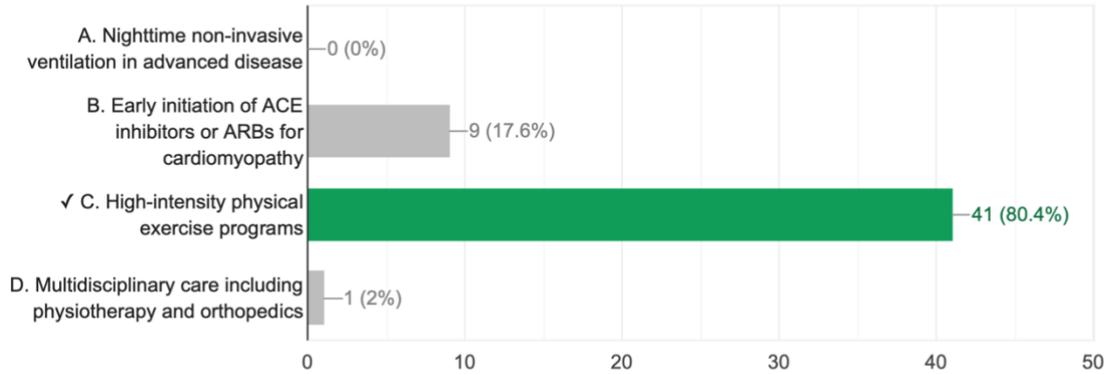
Which of the following correctly describes Becker Muscular Dystrophy (BMD) vs. Duchenne?

39 / 52 correct responses



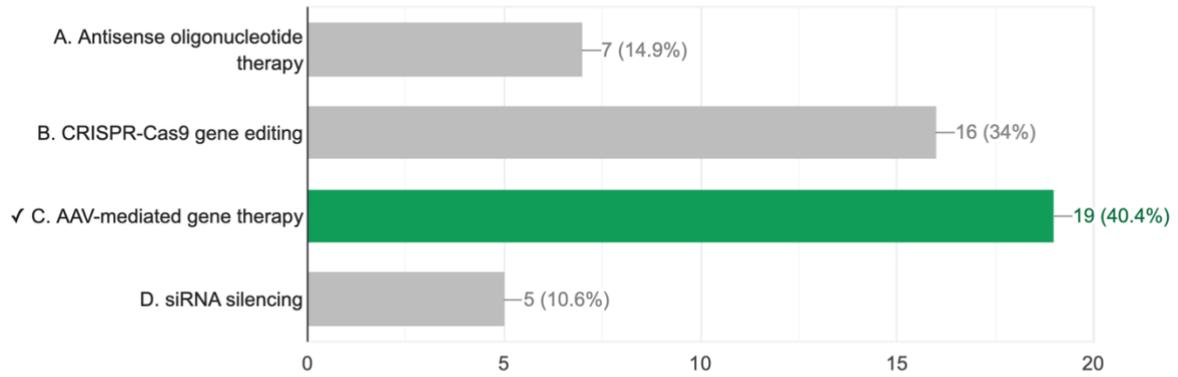
Which of the following is not a current recommended standard of care in DMD?

41 / 51 correct responses



Which investigational therapy targets micro-dystrophin gene replacement delivered by viral vectors?

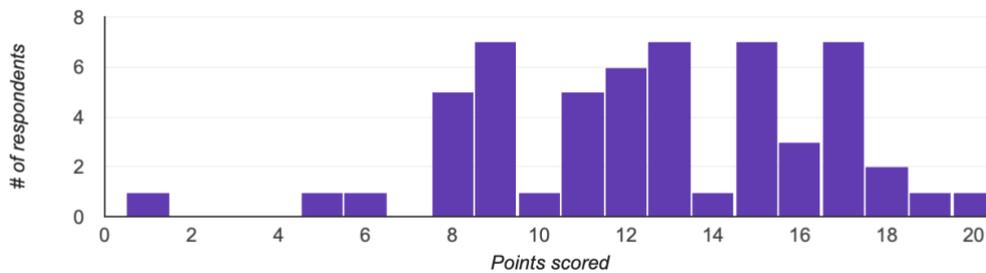
19 / 47 correct responses



Insights

Average	Median	Range
12.57 / 20 points	13 / 20 points	1 - 20 points

Total points distribution



6. Keynote address by Dr. Varnit Shanker at the Constitution Club on DMD





On the occasion of World Duchenne Muscular Dystrophy (DMD) Day on 7th September and World Physiotherapy Day on 8th September, a special awareness and academic session was conducted at the Constitution Club of Rajasthan, Vidhansabha, Jaipur where Dr. Varnit Shanker addressed an audience of over 300 physiotherapists. His lecture focused on the multidisciplinary approach to the treatment and physical rehabilitation of children with DMD, emphasizing the vital role of physiotherapy in maintaining mobility, preventing contractures, and improving quality of life. Dr. Shanker highlighted the importance of early intervention, tailored exercise protocols, and collaborative care involving pediatric neurologists, orthopedicians, and rehabilitation experts. The event also included a **felicitation ceremony for Paralympic athletes, recognizing their inspirational efforts and advocacy for children affected by DMD. The combined celebration symbolized a shared commitment toward advancing neurorehabilitation and promoting inclusion for individuals with neuromuscular disorders.

Overall Impact and Appreciation

The World DMD Day 2025 observance in Jaipur demonstrated how coordinated action between professional bodies, hospitals, and advocacy organizations can create tangible impact.

Each activity contributed uniquely:

Poster Campaign – amplified public and clinical awareness.

Consensus Meet Participation – ensured academic alignment and representation.}

Parent Connect Program – provided emotional and practical support to families.

CME Session – enhanced clinical competence.

DMD Quiz – sustained academic enthusiasm among pediatricians.

Physiotherapists Connect - The event underscored the vital role of physiotherapy and collaborative care

The collective efforts were widely appreciated by both the IAP Rajasthan leadership and national-level pediatric neurology circles, recognizing Jaipur's proactive role in advancing DMD awareness and care.

Under the coordination of Dr. Varnit Shanker, World DMD Day 2025 in Jaipur emerged as an exemplary model of integrated advocacy, blending scientific, educational, and humanitarian efforts. The activities not only increased awareness but also strengthened the local network of professionals dedicated to improving the quality of life of children with Duchenne Muscular Dystrophy.

The momentum generated from this year's event is expected to inspire ongoing programs, research collaborations, and public health initiatives in pediatric neuromuscular care across Rajasthan and beyond.