

THE REST OF YOUR LIFE

Raising a Child With Special Needs

It's been 10 years since Elyse May was born with congenital adrenal hyperplasia, but her mother, Michelle May, M.D., remembers the experience as if it were yesterday.

While Dr. May suspected that her daughter had congenital adrenal hyperplasia, adrenal disorders "are not my area of specialty, so my husband ran to the medical library for books that might

help," recalled Dr. May, a family physician who practices in Phoenix, Ariz. "There I was, having given birth about 12 hours before and reading medical textbooks in my hospital bed."

Once the diagnosis was confirmed, Dr. May and Elyse were discharged home without starting treatment. The endocrinologist told her it was unclear whether Elyse had the mild form of the disease or

the severe form. "He said that if we started to treat the mild form, it would mask the severe form," Dr. May said. Then the endocrinologist went out of town.

Once home, Elyse began vomiting and she became jaundiced and dehydrated. "By the time they decided to start her on the steroids, she was so sick that we put her in the hospital for 3 days," said Dr. May.

"We really did almost lose her. It was

very scary to be a patient in that situation. I couldn't get anyone to listen to me about how sick she was until I finally begged them to let me take her into the hospital. The doctor there said that she probably could have died within 12 hours."

Today, Elyse manages her condition by taking oral steroids three times daily. She wears a MedicAlert bracelet that attracts interest from her peers at school.

"Kids are starting to ask, 'Why do you wear that?'" Dr. May said. "She doesn't want to stand out. She doesn't want to be different. Because of the nature of her condition, if she goes to a sleepover or a birthday party, I have to let parents and other caretakers know about the potential seriousness if she does become ill or injured. I tell them you have to make a double effort to notify us if something happens because she could die of this if she's not treated appropriately."

While the prognosis is excellent for Elyse "as long as she never has an adrenal crisis that is mismanaged, we still have to make sure we do the follow-up appointments and the routine blood work," Dr. May said. "I am now more empathetic to patients who have chronic medical conditions that require a lot of attention. It's easy to get into a role of complacency, or you get busy and you don't do what you should right on time."

Mark Heinz-Graham has a different set of special needs. Born with a moderate range of intellectual functioning, the 27-year-old currently reads at the pre-first grade level, "although he's very motivated to learn how to read," said his mother, Lee Combrinck-Graham, M.D., a psychiatrist who practices in Fairfield County, Conn. "In fact, he has just started with a reading teacher who hopes that now that he is an adult, there are more strategies for helping him to learn. Numbers are elusive [to Mark]. Math is not in his repertoire."

She noted that Mark relishes his full-time job as a grocery store bagger. He also likes to watch TV, play computer games, swim, play the drums, and listen to opera. "He's also in an art class," she said. "He's learning to be more deliberate, careful, and thoughtful."

She said the most difficult part about having a child with special needs is observing the social isolation that occurs. "For example, they can go to a birthday party with regular kids or with special-needs kids. But somehow their participation in it or their 'getting it' is at a different level, so they're sort of on the fringes," Dr. Combrinck-Graham explained.

"If you have a birthday party with six special-needs 6-year-olds, they're all into their own thing. So it's not really a social occasion except they're there and the parents are whooping it up.

"So what does Mark do on Saturday afternoons or Friday nights? That is a really important issue. To some extent he has a much more active social life than many special-needs kids, but it's not anywhere like what a 27-year-old's social life could be."

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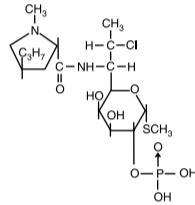
ClindaMax® Lotion

(Clindamycin Phosphate Topical Suspension USP, 1%)
equivalent to 1% (10 mg/mL) clindamycin

FOR EXTERNAL USE ONLY

DESCRIPTION: ClindaMax® Lotion (Clindamycin Phosphate Topical Suspension USP, 1%) contains clindamycin phosphate, USP, at a concentration equivalent to 10 mg clindamycin per milliliter. Clindamycin phosphate is a water soluble ester of the semi-synthetic antibiotic produced by a 7(S)-chloro-substitution of the 7(R)-hydroxyl group of the parent antibiotic lincomycin. The topical lotion contains cetostearyl alcohol (2.5%), glycerin, glyceryl stearate SE (with potassium monostearate), isostearyl alcohol (2.5%), methylparaben (0.3%), sodium lauryl sarcosinate, stearic acid and purified water.

The structural formula is represented below:



Molecular Formula: C₁₈H₃₄ClN₂O₈PS

Molecular Weight: 504.97

The chemical name for clindamycin phosphate is Methyl 7-chloro-6,7,8-trideoxy-6-(1-methyl-trans-4-propyl-L-2-pyrrolidinecarboxamido)-1-thio-L-threo-α-D-galacto-octopyranoside 2-(dihydrogen phosphate).
CLINICAL PHARMACOLOGY: Although clindamycin phosphate is inactive *in vitro*, rapid *in vivo* hydrolysis converts this compound to the antibacterially active clindamycin. Cross resistance has been demonstrated between clindamycin and lincomycin.

Antagonism has been demonstrated between clindamycin and erythromycin.
Following multiple topical applications of clindamycin phosphate at a concentration equivalent to 10 mg clindamycin per mL in an isopropyl alcohol and water solution, very low levels of clindamycin are present in the serum (0-3 ng/mL) and less than 0.2% of the dose is recovered in urine as clindamycin.

Clindamycin activity has been demonstrated in comedones from acne patients. The mean concentration of antibiotic activity in extracted comedones after application of Clindamycin Phosphate Topical Solution for 4 weeks was 597 mcg/g of comedonal material (range 0-1490). Clindamycin *in vitro* inhibits all *Propionibacterium acnes* cultures tested (MICs 0.4 mcg/mL). Free fatty acids on the skin surface have been decreased from approximately 14% to 2% following application of clindamycin.

INDICATIONS AND USAGE: ClindaMax® Lotion (Clindamycin Phosphate Topical Suspension USP, 1%) is indicated in the treatment of acne vulgaris. In view of the potential for diarrhea, bloody diarrhea and pseudomembranous colitis, the physician should consider whether other agents are more appropriate. (See **CONTRAINDICATIONS**, **WARNINGS** and **ADVERSE REACTIONS**.)

CONTRAINDICATIONS: ClindaMax® Lotion (Clindamycin Phosphate Topical Suspension USP, 1%) is contraindicated in individuals with a history of hypersensitivity to preparations containing clindamycin or lincomycin, a history of regional enteritis or ulcerative colitis, or a history of antibiotic-associated colitis.

WARNINGS: Orally and parenterally administered clindamycin has been associated with severe colitis which may result in patient death. Use of the topical formulation of clindamycin results in absorption of the antibiotic from the skin surface. Diarrhea, bloody diarrhea, and colitis (including pseudomembranous colitis) have been reported with the use of topical and systemic clindamycin. Studies indicate a toxin(s) produced by clostridia is one primary cause of antibiotic-associated colitis. The colitis is usually characterized by severe persistent diarrhea and severe abdominal cramps and may be associated with the passage of blood and mucus. Endoscopic examination may reveal pseudomembranous colitis. Stool culture for *Clostridium difficile* and stool assay for *C. difficile* toxin may be helpful diagnostically.

When significant diarrhea occurs, the drug should be discontinued. Large bowel endoscopy should be considered to establish a definitive diagnosis in cases of severe diarrhea.

Antiperistaltic agents such as opiates and diphenoxylate with atropine may prolong and/or worsen the condition. Vancomycin has been found to be effective in the treatment of antibiotic-associated pseudomembranous colitis produced by *Clostridium difficile*. The usual adult dosage is 500 mg to 2 grams of vancomycin orally per day in three to four divided doses administered for 7 to 10 days. Cholestyramine or colestipol resins bind vancomycin *in vitro*. If both a resin and vancomycin are to be administered concurrently, it may be advisable to separate the time of administration of each drug. Diarrhea, colitis, and pseudomembranous colitis have been observed to begin up to several weeks following cessation of oral and parenteral therapy with clindamycin.

PRECAUTIONS: General - ClindaMax® Lotion (Clindamycin Phosphate Topical Suspension USP, 1%) should be prescribed with caution in atopic individuals.

Drug Interactions: Clindamycin has been shown to have neuromuscular blocking properties that may enhance the action of other neuromuscular blocking agents. Therefore it should be used with caution in patients receiving such agents.

Pregnancy: Teratogenic Effects: Pregnancy Category B: Reproduction studies have been performed in rats and mice using subcutaneous and oral doses of clindamycin ranging from 100 to 600 mg/kg/day and have revealed no evidence of impaired fertility or harm to the fetus due to clindamycin. There are, however, no adequate and well-controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

Nursing Mothers: It is not known whether clindamycin is excreted in human milk following use of Clindamycin Phosphate. However, orally and parenterally administered clindamycin has been reported to appear in breast milk. Because of the potential for serious adverse reactions in nursing infants, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

Pediatric Use: Safety and effectiveness in pediatric patients under the age of 12 have not been established.

ADVERSE REACTIONS: In 18 clinical studies of various formulations of topical clindamycin phosphate using placebo vehicle and/or active comparator drugs as controls, patients experienced a number of treatment emergent adverse dermatologic events [see table below].

Treatment Emergent Adverse Event	Number of Patients Reporting Events		
	Solution n= 553 (%)	Gel n= 148 (%)	Lotion n= 160 (%)
Burning	62 (11)	15 (10)	17 (11)
Itching	36 (7)	15 (10)	17 (11)
Burning/Itching	60 (11)	# (-)	# (-)
Dryness	105 (19)	34 (23)	29 (18)
Erythema	86 (16)	10 (7)	22 (14)
Oiliness/Oily Skin	8 (1)	26 (18)	12* (10)
Peeling	61 (11)	# (-)	11 (7)
# not recorded			
* of 126 subjects			

Orally and parenterally administered clindamycin has been associated with severe colitis which may end fatally. Cases of diarrhea, bloody diarrhea and colitis (including pseudomembranous colitis) have been reported as adverse reactions in patients treated with oral and parenteral formulations of clindamycin and rarely with topical clindamycin (see **WARNINGS**).

Abdominal pain and gastrointestinal disturbances as well as gram-negative folliculitis have also been reported in association with the use of topical formulations of clindamycin.

OVERDOSAGE: Topically applied ClindaMax® Lotion (Clindamycin Phosphate Topical Suspension USP, 1%) can be absorbed in sufficient amounts to produce systemic effects. (See **WARNINGS**.)
DOSAGE AND ADMINISTRATION: Apply a thin film of ClindaMax® Lotion (Clindamycin Phosphate Topical Suspension USP, 1%) twice daily to affected area.

Shake well immediately before using.
Keep in container and keep tightly closed.

HOW SUPPLIED: ClindaMax® Lotion (Clindamycin Phosphate Topical Suspension USP, 1%) containing clindamycin phosphate equivalent to 10 mg clindamycin per mL, is supplied as follows:
NDC 0462-0391-60 60 mL bottle

Store at controlled room temperature 15° - 30° C (59° - 86°F).
Protect from freezing. (See USP.)


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That's not to say family members don't include him in their regular social activities. They do. In fact, she said, "when our group of friends invites us for dinner, they usually invite him, too. Most of our friends like him and make an effort to include him. They understand that if he comes to dinner, there's going to be a part of the evening in which he's not going to be interested, and he'll go off and watch television."

She added that families of special-needs children "shouldn't feel ashamed or try to hide their kid and shouldn't feel reluctant to invite people in to help.

For instance, Mark is fairly independent. Sometimes we go away overnight and might say to one of our friends, 'Would you give him a call and say hi and see if he's alright?' Or sometimes when we go away someone will stay with him in the house. We do this so he has a larger circle of people paying attention to him while we're away. I've met some parents [of special-needs children] who say, 'Nobody would want to do that for my child.' That's not true. People really do want to know what to do, so they need to be included with your friends and family. Raising this child, loving this child, and making this child feel welcome is a collective activity. None of the tasks should be assigned to just one person."

Dr. Combrinck-Graham noted that it took a while for her own mother to accept Mark as he became an adult. "She likes to have intellectual conversations and she constantly displayed disappointment [in him], which I don't even think she was aware of," she said. "I finally said to her, 'He's not what you wanted him to be, but he is who he is. You're missing out on a great opportunity, so why don't you get over it?' Now, most of the time she's really getting a kick out of him."

Elisa Nicholas, M.D., reiterated the importance of focusing on the assets of a child with special needs. But she pointed out that the competitive, achievement-focused culture of medicine can pose a challenge to that effort.

"If you sit around a doctor's dining room and everybody's talking about their over-achieving child, and you're simply trying to get your child to walk and talk, it is very difficult," said Dr. Nicholas, whose 16-year-old son, Tom, has cerebellar ataxia. He copes with difficulty walking, general coordination problems, and cognitive challenges.

Tom—the first physically challenged student to be fully integrated into the Hermosa Beach (Calif.) School District—wears braces on his feet and uses a walker, crutches, or a wheelchair for mobility. "He can dress himself, but he will never be able to put his braces on by himself," said Dr. Nicholas, a pediatrician who directs The Children's Clinic, Serving Children and Their Families, a system of six not-for-profit community health centers in Long Beach, Calif. "He's always going to need some assistance."

When Tom was diagnosed with the condition at age 16 months, "we were all depressed and frightened in not knowing what the future might hold," she said. "It's difficult because I think most physicians to some extent are able to control their destiny, [the idea that] if you work hard enough you

can achieve something. But in these kinds of situations, you're not in control."

She also knows the caregiver role consumes many parents.

"I think trying to achieve a balance is truly a great challenge," she said. "I want Tom to reach his greatest potential. If that means I have to make personal sacrifices, I will do that. But it's very difficult to find that balance, because it can become all-consuming. While it can become all-consuming, it is imperative to take time for yourself, your spouse, and your other children." ■

By Doug Brunk, San Diego Bureau



Dr. Michelle May says that her daughter Elyse's congenital adrenal hyperplasia has made her more empathetic to patients with attention-consuming chronic health conditions.



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