

## Spina Bifida Guideline

# Latex allergy guidelines for people with spina bifida

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**Abstract.** An estimated 85% of individuals with spina bifida (SB) survive into adulthood, warranting SB-specific transition to adult healthcare guidelines to address the diverse and complex medical, adaptive, and social needs particular to this condition. Latex allergy constitutes one important health concern for this population that requires ongoing and life-long evidence-based management. This article discusses management of latex allergy according to the SB Latex Allergy Healthcare Guidelines from the 2018 Spina Bifida Association's Fourth Edition of the Guidelines for the Care of People with Spina Bifida, reviews current care models in which such latex allergy guidelines can be implemented, and explores further relevant research topics in SB care relative to latex allergy.

**Keywords:** Myelomeningocele, allergy, spina bifida, latex, latex allergy, *Hevea* latex, latex-fruit syndrome, neural tube defects

## 1. Introduction

The history of latex allergy and its intersection with people with spina bifida dates back to the late 1980s in the United States with the advent of Universal Precautions. At that time, in the midst of the HIV outbreaks, there was a dramatic demand for latex materials. Furthermore, there was little to no international regulation relative to the quality of the latex being processed and used for manufacture of personal protective equipment, such as gloves, or for medical equipment such as “red rubber catheters.”

Derived from the plant *Hevea Brasiliensis*, natural rubber undergoes a manufacturing process resulting in

a final latex product composed of numerous proteins, lipids, amino acids, nucleotides, co-factors, and cis-1,4,-polyisoprene. Even with stringent regulation on the usual vulcanization and purification processes employed in the manufacturing of latex, up to 2–3% of residual free proteins remain in the final product [1]. With lower standards of production globally in the 1980s and early 1990s, there existed a high potential for allergic reactions to the latex.

Specifically pertaining to individuals with spina bifida, clinical reports of severe allergic reactions, including anaphylaxis, and remarkable reports of life-threatening events related to surgeries began to surface. Subsequently, latex allergy was found to be an associated trigger for many of these allergic reactions accompanying surgeries as well as episodes of systemic allergic responses to exposure in the natural environments of home, school, and community [2,3].

The early 1990s brought focused efforts to begin to systematically avoid exposing infants and children with spina bifida to natural rubber products. This was partic-

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ularly a focus in major children's hospitals where heavy exposure to latex was common; for example, rubber catheters and latex gloves were often used in neonatal intensive care units, newborn nurseries, operating rooms, and pediatric emergency departments. Eventually, this avoidance extended to many primary pediatric offices and pediatric dental offices.

Exposure to latex remains a concern to many individuals with spina bifida. Notably, natural rubber products remain in use across multiple environments today: hospitals, clinics, schools, churches, homes, and community facilities. Exposure to latex occurs both by direct contact and inhalation of powder containing latex. Symptomatic responses to latex in the allergic individual may be classified as "mild" or "moderate" reactions, such as skin irritations, rash, hives, flushed cheeks, itchy eyes, or sneezing. However, those responses can immediately progress or evolve to more dramatic systemic responses such as generalized urticaria, wheezing, coughing, periorbital erythema and swelling, nausea and vomiting, and anaphylaxis [4].

In the interval since the publication of the Healthcare Guidelines for People with Spina Bifida, there have been a number of subsequently published articles on the subject of latex allergy in this population. Several of these are listed in the references below. However, most are either categorized as review articles, quality improvement reports that substantiate previously described findings, recapitulations of the concepts outlined in the guidelines, or re-statements of best practice guidelines based on clinical practice outcomes [5–9]. Ebo et al. provided a useful overview of the latex IgE reactivity profile and its use in monitoring and assessing latex allergy [10]. The present work further integrates the prior guidelines into clinical settings, assisting the clinician in applying them to the care of people with spina bifida across the lifespan and highlighting areas for future research [11].

## 2. Goals for better outcomes related to latex allergy concerns

In preparing to outline healthcare guidelines for clinicians and families in partnership, the workgroup first considered the goals and hoped-for outcomes from application of the guidelines. With the endpoints being considered, several over-arching goals for the guidelines were set out. The working group aimed to have families of individuals with spina bifida (and the individuals as they reach maturity) demonstrate awareness

of the history of latex allergy and the importance of avoidance of latex as the primary medical intervention against life-threatening allergic events. As a component of this, families and individuals require education and intermittent reminders of the signs and symptoms of latex allergy. If, over time, the individual becomes sensitized and demonstrates systemic allergic manifestation, it is crucial that the person know about medical "alert" options in the event of a systemic and/or anaphylactic reaction. Today, the use of a medical information app on the personal phone increasingly constitutes the "go to" avenue in urgent care and emergency departments; in addition, the classic medical alert bracelet continues to be encouraged.

The goals outlined were designed to be practical and achievable by the individual, family members, and clinicians working with them. The desired primary, secondary and tertiary outcomes from the use of latex allergy guideline consisted of the following:

### 2.1. Primary outcomes

- To help people with spina bifida avoid all direct skin contact to natural rubber latex protein and latex-containing products in the environment
- Provide awareness and understanding that latex allergy remains a relatively high-risk condition for this population
- To help people with spina bifida to better understand that latex-containing products can still be a concern in activities of daily living, medical/surgical care, and community participation
- To help people with spina bifida be knowledgeable of and aware of signs and symptoms of latex allergy

### 2.2. Secondary outcomes

- People with spina bifida and *known* latex allergy should have medical-alert identification with them at all times (bracelet, personal phone medical information app, etc.)
- People with spina bifida and *known* latex allergy and their families should know the signs of life-threatening anaphylaxis

### 2.3. Tertiary outcome

- People with spina bifida and *known* latex allergy and their families should have a pre-arranged plan of action in the event of a severe, life-threatening anaphylactic reaction

Table 1  
Clinical questions that informed the latex allergy guidelines

Age group	Clinical questions
0–3 years	<ol style="list-style-type: none"> <li>1. What knowledge do parents and caregivers of infants and toddlers with spina bifida need with regard to risk for latex allergy?</li> <li>2. What activities and objects/materials that children in this age group and their families come across frequently present risks for latex allergy?</li> <li>3. How can parents and caregivers of infants and toddlers with spina bifida keep them safe with respect to their risk for latex allergies?</li> <li>4. What is the role of clinicians and health care facilities in keeping children safe?</li> <li>5. What are the considerations for appropriate medical identification of the child with latex allergy?</li> </ol>
3–6 years	<ol style="list-style-type: none"> <li>1. Where are children of this age group most likely do encounter objects containing latex?</li> <li>2. What are the considerations related to classrooms and community play areas?</li> <li>3. What knowledge to parents, caregivers, teachers and school staff need to eliminate exposure to latex?</li> <li>4. How can the children enjoy parties with friends and explore new foods while avoiding latex?</li> <li>5. What basic knowledge and emotional readiness do the children themselves need to keep them safe from latex exposure?</li> <li>6. How should children with known latex allergy be managed when there are concerns about cross-reactivity?</li> </ol>
6–13 years	<ol style="list-style-type: none"> <li>1. How can knowledge and awareness of latex exposure and allergy risk be maintained and built upon by parents, caregivers, clinicians, and teachers as children continue to mature, taking into account the child's learning and behavioral needs?</li> <li>2. What environments where the children spend time pose the greatest risk of latex exposure?</li> <li>3. Are there potential food exposures stemming from hidden food preparation practices?</li> <li>4. What is the care plan, including medications, for children with a known latex allergy who have a reaction?</li> </ol>
13–18 years	<ol style="list-style-type: none"> <li>1. How can the adolescent with spina bifida increase their knowledge and awareness of latex allergy risk so that they become more independent in keeping themselves safe, according to their developmental level?</li> <li>2. What are new risks that arise related to the widening sphere of social and recreational activities for this age group?</li> <li>3. What do teens need to know about latex allergy risks and contraceptives before they initiate sexual activity?</li> <li>4. How can the care plan, including medications, be better understood by the adolescent, in the context of cognitive and behavioral status?</li> </ol>
Adults	<ol style="list-style-type: none"> <li>1. What is the baseline understanding of the individual with spina bifida regarding latex allergy risk across the different settings they encounter, including occupational settings, and how can learning gaps be filled?</li> <li>2. How will protection from latex allergy risk impact sexuality and relationships?</li> <li>3. For the individual with known latex allergy, what are the salient needs related to maintaining updated medication and treatment plans?</li> <li>4. How should the development of new latex allergy be managed?</li> </ol>

### 3. Methodology

In keeping with the protocol used for construction of the Healthcare guidelines, the working group on latex allergies followed the uniform methodology set out for the project by Dicianno et.al. [12] More description of the workgroup's process is outlined in the final version of the Healthcare guidelines found at <https://www.spinabifidaassociation.org/guidelines/latex>.

A workgroup for the topic was identified and appointed and consisted of: Richard Adams, MD (Chair); Kevin Kelly, MD; Sue Lockwood, Allergy and Asthma Network; Suzanne McKee, RN BSN; Candice Walker, PhD; Heather Burns, BA.

To assure an extensive scoping review of the literature since the publication of the prior 3<sup>rd</sup> Edition of the Guidelines, each of the workgroup members reviewed the interval literature for research and outcomes-based studies related to latex, latex allergy, spina bifida, and myelomeningocele. This was greatly assisted by the Medical Librarian at Scottish Rite Hospital in Dallas,

TX. Peer-reviewed publications that were reviews only were searched for potential references not otherwise found through the scoping review. The salient updated studies are listed in the Healthcare guidelines chapter on Latex Allergy.

The workgroup compiled guidelines for each of the age groups listed and then presented these to the other workgroups involved with the Healthcare guidelines for expert response and suggestions. This process was repeated after a first editing. Specific suggestions were constructed by consensus, given the status of research published and the current knowledge base about latex allergy in spina bifida.

### 4. Clinical questions framing the guidelines

The guidelines emerged from clinical questions among the workgroup that related to caring for people with spina bifida and risk for latex allergy. These varied by the age group of the people with spina bifida be-

ing considered and reflect environmental, psychosocial and medical factors. Table 1 presents the workgroup's questions according to age group.

## 5. Results: Guidelines related to latex allergy for people with spina bifida

Outlined according to age groups, the guidelines related to latex allergy strive to educate people with spina bifida and their families about these risks, and to offer suggestions for avoidance to minimize potentially life-threatening events. Importantly, differing risks of exposure occur in various environmental settings across the lifespan. Likewise, the shift in emphasis related to avoidance, prevention, and actions move from caregiver to the individuals, themselves, as they move through successive developmental stages. Table 2 provides an outline. As they progress through development, and according to their cognitive and behavioral status, the focus of education and care plan responsibilities transition from the family to the individual. In addition, as the person matures, they encounter more environments and settings which may pose new latex exposure risks. Furthermore, in adolescence and adulthood, needs emerge regarding relationships and sexuality as well as occupational environments.

### 5.1. Early years

Avoidance of exposure to latex should begin in the operating room for those undergoing prenatal surgical closure and in the delivery room and the neonatal nursery for all infants with spina bifida. When possible, birthing centers for children with spina bifida should have a "latex free" designation. To that end, working with hospital purchasing personnel to assure that no products with latex enter the hospital comprises a useful first step.

Expectant prenatal counseling with the surgeon and the spina bifida team physician, emphasizing latex avoidance, can begin the conversation, which should recur over the years. This will help families as they prepare to bring the infant home: i.e., latex-free pacifiers, bottles, toys, etc.

Similarly, anticipatory guidance delivered at infant/toddler "well child visits" for children with spina bifida should include education regarding the signs and symptoms of latex allergic reactions. Clearly, the types of toys, personal possessions, and the home environment will change over time, necessitating a develop-

mentally tailored approach. Also, consideration must be given to educating day care and school staff, teachers, and other caregivers (grandparents, etc.) about the need to avoid unnecessary exposure.

Children at the pre-K to kindergarten age are capable of identifying some examples of latex products in their environment and they should be encouraged to proactively ask their teachers and other responsible adults (i.e., doctors, nurses, therapists, dentists, or others) about the presence of latex objects of concern in the immediate environment (i.e., rubber balls, balloons, adhesive bandages, etc.) [2,4,13–33].

### 5.2. School years

During this stage, education about latex allergy risks should gradually shift from parents and caregivers to the elementary school aged child with spina bifida. These risks should be discussed at each well child visit while assuring monitoring and support from parents/caregivers. Moreover, health care clinicians should encourage the child to ask questions and provide them with developmentally appropriate responses.

Children in this age group participate in a wider range of environments, including those at home, school, church, and community organizations. In this age group, they increasingly participate in informal activities and have interactions during "sleep overs" at friends' homes, and visits to restaurants, camps, and shopping malls. In addition, there may be frequent visits to medical and dental offices.

As it remains unrealistic that each of these differing environments will achieve a "latex free" status, it becomes increasingly important for the growing child to assume a proactive role in self-monitoring for latex allergy.

For those children who have tested positive via IgE immunofluorescence studies and have demonstrated clinical signs and symptoms of an allergic response to latex, they and their parents should be encouraged to have available diphenhydramine and self-injectable epinephrine at all times. In addition, the child should learn that these medications need to be available when on outings away from home and school.

Increasingly, questions arise related to what has come to be called "latex fruit syndrome." This syndrome involves protein allergens (for example, *Hev b 6* heien) present in some latex products and making up a notable percentage of the total protein. Some evidence exists pointing to cross-reactivity to certain proteins in a group of fruits, for example, bananas, avocados,

Table 2  
Spina bifida latex allergy guidelines for clinicians - summaries by age groups across the lifespan

Age group	Guidelines	Evidence
0–3 years	1. Inform parents and caregivers for infants and toddlers about latex allergy and ways to provide safe infant care while avoiding exposure to latex products	[2, 4, 13–33]
	2. In clinical practice and healthcare facilities, avoid products that contain latex when caring for infants/toddlers with spina bifida	[2, 4, 13–33]
	3. Inform medical staff and families of potential latex-containing products such as bottle nipples, pacifiers, teething rings, toys, and medical supplies (adhesive bandages, catheters, etc.)	[2, 4, 13–33]
	4. As toddlers show increased mobility, remind families that this puts the child at greater risk for exposure	[2, 4, 13–33]
	5. All toys should be evaluated to assure they are latex-free	[2, 4, 13–33]
	6. Encourage families to practice latex avoidance	[2, 4, 13–33]
	7. Encourage families of children who have demonstrated latex allergy to utilize medical identification for the child	[2, 4, 13–33]
3–6 years	1. As children enter into preschool and kindergarten, screen for toys and products in the classroom and other school settings that may be latex-containing	[2, 4, 13–33]
	2. Discuss avoidance principles with school staff (rubber balloons at parties, school activities, field trips, restaurants, other gatherings for events and activities)	[2, 4, 13–33]
	3. Teach children with spina bifida to be proactive and confident in asking questions about items that may contain latex in their environments	[2, 4, 13–33]
	4. Teach children, at a basic level, to avoid latex products and to identify latex-free substitutes (example: Mylar balloons for celebrations)	[2, 4, 13–33]
	5. Instruct families to check that food made in public venues has been prepared with latex-free gloves	[2, 4, 13–33]
	6. Initiate referral to an allergist when the child has <i>known</i> latex allergy but it is not known if he/she is allergic to cross-reacting foods	[2, 4, 13–33]
6–13 years	1. Increase education efforts to the children about latex identification and the importance of continued avoidance by reviewing the principles behind latex allergy prevention; encourage questions from the child and provide developmentally-appropriate answers	[2, 4, 13–33]
	2. Discuss potential latex exposures across home, school, community activities	[2, 4, 13–33]
	3. Educate about possible “unseen” exposures (example: food preparation in restaurants where latex gloves are used)	[2, 4, 13–33]
	4. For those with <i>known</i> latex allergy, instruct the child and the family/caregivers that diphenhydramine (oral) and epinephrine in a dose-appropriate self-administration form for injection need to be immediately available at all times	[2, 4, 13–33]
	5. As above, in children with <i>known</i> latex allergy and concerns of cross-reactivity, initiate a referral to an allergist	[2, 4, 13–33]
13–18 years	1. In this particular age group wherein risk-taking is a common element in their developmental progression, provide updated education about their role in avoidance of products containing latex	[17–19, 21, 24–34]
	2. Assist the teen in better understanding allergy risks in home, school, and community settings (restaurants, sports venues, etc.)	[17–19, 21, 24–34]
	3. Educate teens about latex-safe contraceptive products before they become sexually active	[17–19, 21, 24–34]
	4. For teens with <i>known</i> latex allergy, review again the importance of readily available diphenhydramine (oral) and self-administered epinephrine; help to clarify a plan of decision-making and action with the teen	[17–19, 21, 24–34]
Adults	1. Clarify with the adult their understanding of prevention, precautions, and avoidance of latex and natural rubber products at home, the workplace, and the community; provide answers to questions	[2, 3, 15–19, 21, 24–34, 36, 37]
	2. Review importance of avoiding latex-containing products for contraception in the person with spina bifida and the partner	[2, 3, 15–19, 21, 24–34, 36, 37]
	3. Clarify the need for new prescriptions / refills for diphenhydramine, self-injectable epinephrine; review protocols for administration; review a plan of care regarding if/when to use these medications	[2, 3, 15–19, 21, 24–34, 36, 37]
	4. If new allergic symptoms are noted in a person with <i>known</i> latex allergy, refer to allergist for consideration of further testing	[2, 3, 15–19, 21, 24–34, 36, 37]

kiwi, and chestnuts. While these are the more frequently cited examples, there are at least 25 other fruits that *may* have some level of cross-reactivity with latex. In these cases, allergy testing can help to clarify such triggers [17–19,21,24–36].

### 5.3. Adolescence

The typical developmental challenges of adolescence also impact youth with spina bifida. Adolescents' denial of medical issues, their desire to "fit in" and their tendency for risk-taking can all contribute to greater exposure to latex in the environment. To address these challenges, the concept of motivational interviewing can be applied during clinical visits with the adolescent with spina bifida. As these youth "experiment" and explore newfound freedoms and wider venues, they benefit from enhanced supports to help shift the "locus of control" in managing latex risk from parents and caregivers to themselves.

With respect to sexuality, any related educational conversations and counseling must also include the subject of latex allergy. Latex-free contraceptives are critical in avoidance of unplanned pregnancy, sexually transmitted diseases, and unwanted latex allergy symptoms.

Again, for those who have tested positive and demonstrated systemic signs of allergy or even anaphylactic responses, the availability of diphenhydramine and epinephrine remains important. Helping the adolescent to develop, process (including cognitively, emotionally, and socially), and apply a proactive action plan for systemic reactions can be life-saving. Clinicians should customize the approach based on the diverse executive functioning, learning and behavioral differences that may manifest in youth with spina bifida. [17–19,21,24–34].

### 5.4. Adult

Similar to their parents having to assist in the school in assuring a latex-free environment for their classrooms, adults with spina bifida entering into a workplace now need to assume a similar diligence in surveying their environment and educating the supervisor of the workplace about latex and its risks. The occupational health nurse or staff can represent allies in this endeavor. On a personal level, the same issues related to contraceptives, as mentioned above, hold true.

Over time, if any new allergic symptoms present in the person with a known latex allergy, a referral to an

allergy specialist should be made for consideration of further testing. Furthermore, for the adult with spina bifida with a known past history of latex allergy, dosages and prescriptions for self-injectable epinephrine should be reviewed and updated periodically [2,3,15–19,21,24–34,36,37].

## 6. Areas for future research

As the total volume of randomized controlled or population studies about latex allergies in spina bifida remain minimal, the guideline recommendations for each of the above categories emerged primarily by consensus of experts in allergy/immunology, spina bifida clinical care, and family insight. Clearly, there remain many questions and multiple opportunities for future research endeavors [38].

The Latex Allergy Workgroup offered a number of suggestions going forward. Examples include:

- Provide updated measures on the true incidence and prevalence of latex allergy among people with spina bifida and among others with frequent exposure to latex products (nurses, environmental services workers, others who routinely use latex products) for comparison.
- Conduct descriptive studies of people with spina bifida who "turn positive," addressing questions about immunity, genetic differences, exposure histories, etc.
- Undertake animal model studies on the clinical impact of latex powder exposure to increase knowledge about the risk of latex gloves in the community.
- Address the following questions:
  - \* How can we best come to consensus on most effective preventive screening protocols? [39]
  - \* How can we become more informed about the realities and the extent of risk in cross-reactivity of latex allergy and certain foods?

## 7. Conclusion

Until better scientific explanations are available to specifically direct preventive measures and treatment for people with spina bifida who have latex allergy issues, the consensus remains: this group should continue to avoid skin contact with latex protein in the environment and should avoid inhalation of powder that contains latex particles. This practice of avoidance should

extend to latex-containing products used for activities of daily living, medical care, dental care, and community integration across the life span. Moreover, education and guidance pertaining to latex allergy risks should involve a partnership between the clinician and the individual and the family, with increasing self-management for the maturing individual, tailored to cognitive and developmental status.

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The Spina Bifida Association has already embarked on a systematic process for reviewing and updating the guidelines. Future guidelines updates will be made available as they are completed.

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## Conflict of interest

The authors have no conflict of interest to report.

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<sup>1</sup>Note: the above article begins: The average prevalence of latex allergy and sensitization worldwide remains 97% and 124% among healthcare workers, 7.2% and 30.4% among susceptible patients, and 4.3% and 2.1% among general population.



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